Supporting the Journey of Pregnancy for Women with Type 1 Diabetes

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CONTENTS

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Over the many years I have worked in diabetes and mental health, I have spoken with hundreds of women with diabetes about their worries, dreams and concerns, in relation to becoming pregnant and having a healthy baby. Listening to their fears, anxieties and ultimate joys of becoming a mother, led me to a PhD topic both dear to my heart and one that is under-researched. As a woman living with type 1 diabetes since 1979 who was told at the age of 12 years-old, I would probably never have children, and if I did, they would most likely be born deformed or worse, stillborn, this is not just a professional or an Academic journey, but a personal one. I am now the mother of three healthy, strapping boys who are my absolute joy, and have lived with type 1 diabetes for most of my life. It was important during this work therefore, that I continually aimed to step back and separate my own experiences from those of the women who joined me on this journey, so that I would not place my lens upon their experiences. At the same time, this has given me a unique perspective from which to view pregnancy and motherhood for women with type 1 diabetes.

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ABSTRACT

Diabetes is one of the most common medical conditions complicating pregnancy. Despite improvements in care, management of pregnancy for women with type 1 diabetes remains challenging. Adverse outcomes include congenital anomalies, stillbirth and perinatal mortality. There is well established evidence that the risks can be significantly reduced by attendance at pre-pregnancy counselling. However, for a variety of reasons, uptake is persistently low. Contemplation of pregnancy is an opportune time to offer information about pre-pregnancy counselling. This time-phase of the pregnancy journey may last many years, and precedes pregnancy planning. Women with type 1 diabetes might be seeking knowledge, reassurance, and a sense of optimism about pregnancy from their peers, via internet-based resources, before and/or instead of, approaching a health care professional. Along with peer support, internet-based pregnancy resources can offer balanced information about the risks of pregnancy, coupled with positive stories about becoming and being a mother with type 1 diabetes.

Women with type 1 diabetes may expect more intensive medical intervention during pregnancy and can experience reassurance from this, however the intense focus on diabetes management can detract from the experience of pregnancy itself. There can be mental health impacts and increased experiences of diabetes specific distress, that might be different to other times of their lives. Communication about pregnancy needs to be balanced and timely.

More information is needed for both women with type 1 diabetes and health care professionals, about what pre-pregnancy counselling involves, where it is available and why it is important. There should be a person-centred approach.

This Thesis firstly explores the pregnancy journey for women with type 1 diabetes through a thematic analysis of online diabetes counselling records. This results in the development of a theoretically driven model of the pregnancy journey, which highlights the time-phases, from Contemplation to Motherhood. Focusing on the Contemplation phase, I then develop a prototype Contemplating Pregnancy in Diabetes Communication Support Questionnaire, to enhance this journey. The aim is to open up conversation about preparedness for pregnancy, rather than to assess or affect, outcomes. This is now ready for further testing. Finally, I present a meta-synthesis of the current themes in the qualitative literature around using internet-based programmes and resources to offer women with type 1 diabetes pregnancy information and support.

I conclude that in order to reduce the risks of adverse outcomes, pregnancy information, and in particular the importance of pre-pregnancy counselling, needs to be freely available across the child-bearing years. Discussions about pregnancy planning should occur earlier and more often. I recommend discussions about preparedness for pregnancy should include both the desirable health related behaviours for a healthy pregnancy and an understanding of the personal, social and psychological resources available for the journey. I suggest that to encourage positive pregnancy conversations between health care professionals and women with type 1 diabetes and allow women to drive their seeking of pregnancy information, more internet-based pregnancy and diabetes resources must be developed and evaluated. Women with type 1 diabetes should be included in the development and delivery of these.

DECLARATION

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in my name in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission in my name for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint award of this degree. The author acknowledges that copyright of published works contained within this thesis resides with the copyright holder(s) of those works. I give permission for the digital version of my thesis to be made available on the web, via the University's digital research repository, the Library Search and also through web search engines, unless permission has been granted by the University to restrict access for a period of time. I acknowledge the support I have received for my research through the provision of an Australian Government Research Training Program Scholarship.

Helen Edwards DATE: 16/7/19

CHAPTER 1. BACKGROUND INTRODUCTION AND LITERATURE REVIEW

OPENING SUMMARY STATEMENT

With increased knowledge and advancements in diabetes management, the outcomes of pregnancy for women with type 1 diabetes have improved, from usually being fatal for both mother and child, to expectations that a healthy pregnancy is possible. This positivity is supported by the St. Vincent Declaration of 1989 (Colstrup, Mathiesen, Damm, Jensen, & Ringholm, 2013) which suggested optimistically that pregnancy outcomes for women with type 1 diabetes should be comparable to those without diabetes within five years (Colstrup et al., 2013). However, the outcomes of numerous studies, including a review of 12 population-based studies in 2013 (Colstrup et al., 2013), show that the risk of adverse pregnancy outcomes remains two to five times higher for women with type 1 diabetes, compared with women without diabetes; the risks of congenital malformations, stillbirths and neonatal death, are 3–10 times greater for women with type 1 diabetes, compared to women without diabetes; and that the goals of the St. Vincent declaration have certainly not been achieved.

These results show that despite advancements, the management of pregnancy for women with type 1 diabetes remains challenging. This includes the fact that reaching the targets recommended for blood glucose levels, in order to achieve a healthy pregnancy and baby, without significant hypoglycaemia, requires women with type 1 diabetes to be highly motivated and knowledgeable, and to have access to support from a qualified and experienced health care team, from the pre-pregnancy stage (Meltzer, 2010).

However, not all women with type 1 diabetes will have access to properly qualified and experienced diabetes and pregnancy specialist teams, and some women may lack adequate family and peer support, which have also been shown to be important (Letherby, Stephen, & Stenhouse, 2012; Meltzer, 2010). Additionally, diabetes management technologies such as continuous glucose monitoring and pump therapy, may improve the chances of safely

reaching target glucose levels, but these may be unavailable for economic or pragmatic reasons to many women with type 1 diabetes (Feig et al., 2016; Meltzer, 2010; Stewart et al., 2016).

In Australia, data derived from the National Hospital Morbidity Database (NHMD) show that between 2005–06 to 2007–08, 47,143 (5.6%) women who gave birth in Australian hospitals had a diagnosis of diabetes in pregnancy: 0.3% had pre-existing type 1 diabetes, 0.3% had pre-existing type 2 diabetes and 4.9% had gestational diabetes (GDM). Mothers with pre-existing diabetes, whether type 1 or type 2, had greater rates of the majority of adverse effects of pregnancy, labour and delivery, when compared with those who had GDM, or who did not have diabetes. For women with type 1 diabetes, the rates of caesarean section, hypertension and pre-term birth, were also greater than for mothers with type 2 diabetes. Overall, women with type 1 diabetes were more likely to be hypertensive, give birth pre-term, have an induced labour, have their labour induced pre-term, have a caesarean section, and stay in hospital for longer, both before and after, giving birth, than any other group (AIHW, 2010; Huhta, Hirvonen, & Huotari, 2018).

In the 2-year period from 2014–2015, more than 45,000 mothers who gave birth in Australia (excluding Victoria) had diabetes, representing about 9.9% of all births recorded in the National Perinatal Data Collection. Of all births recorded, about 40,500 (8.9%) had gestational diabetes, and 4,700 (1.0%) had pre-existing diabetes), representing an almost doubling of these rates (AIHW, 2019). As with the findings from 2005–06 to 2007–08, compared with mothers who did not have diabetes during pregnancy, those with pre-existing diabetes and gestational diabetes, had higher rates of caesarean section, induced labour, pre-existing and gestational hypertension, and pre-eclampsia. They also experienced longer antenatal and postnatal stays in hospital of 5 or more days (AIHW, 2019). Mothers with pre-existing diabetes experienced complications at a higher rate than mothers without diabetes.

Compared to babies of mothers with gestational diabetes or no diabetes, babies of mothers with pre-existing diabetes had higher rates of pre-term birth, stillbirth, low and high birthweight, low Apgar score, resuscitation, and special care nursery/ neonatal intensive care unit admission, and stayed longer in hospital. Babies of mothers with gestational diabetes had higher rates of complications than babies of mothers with no diabetes, but showed similar levels of risk as babies of mothers with no diabetes, for high birthweight and low Apgar score (AIHW, 2019). Accordingly, the risks for women with type 1 diabetes and their babies remain major, and given the more intensive medical care required and longer hospital stays for both mother and baby, the resultant health-care costs are substantial (Colstrup et al., 2013; Egan et al., 2017c; Egan et al., 2017d).

The risk of adverse outcomes for women with type 1 diabetes and their babies has been shown (discussed further in the following literature review), to be substantially reduced through attendance at pre-pregnancy counselling, where women can develop preparedness for pregnancy, and ensure the best possible environment for a developing baby (Soubeiga, Sia, & Gauvin, 2014). Awareness of the importance of pre-pregnancy counselling, easy access to this, and positive communication about pregnancy from health care professionals, have all been shown to increase the likelihood that a woman with type 1 diabetes will attend pre-pregnancy counselling when she is ready to plan for a pregnancy (Morrison et al., 2018; Murphy et al., 2010b; Owens, Egan, Carmody, & Dunne, 2016). Offering information about pregnancy planning across the child-bearing years, via multiple platforms, including internet-based support with reliable information, interactive support and social networking, is recommended (Sparud-Lundin, Ranerup, & Berg, 2011a).

Both life management and personal wellbeing can be increased substantially through the development of preparedness, and preparedness can be seen as a cognitive motivational construct, supported by self-efficacy and strong social connections (Endres, Sharp, Haney, &

Dooley, 2004; George, 2005; Salmela-Aro et al., 2012). Preparedness provides a person with the ability to deal effectively with, and respond to, events and outcomes that cannot easily be predicted, or controlled – being prepared for whatever comes (Sweeny, Carroll & Shepperd, 2006). Because the outcomes and events during pregnancy cannot be controlled or predicted, possessing knowledge about diabetes and pregnancy, self-efficacy, and optimism that a healthy pregnancy and baby are possible, along with suitable support systems, have been shown to be important for women with type 1 diabetes (Linden, Sparud-Lundin, Adolfsson, & Berg, 2016; Rasmussen, 2012, 2013; Sweeny, Carroll, & Shepperd, 2006).

Essentially, pre-pregnancy counselling is health care focused on developing this preparedness for pregnancy. For example, in pregnancy with type 1 diabetes, both high dose folic acid supplementation and tight glycaemic management prior to conception, have been shown to reduce the risk of adverse outcomes substantially. They are, accordingly, important components of pregnancy preparation, usually discussed in pre-pregnancy counselling (Morrison et al., 2018; Neff et al., 2014; Owens et al., 2016; Pearson, Kernaghan, Lee, & Penney, 2007; Soubeiga et al., 2014; Wahabi, Alzeidan, & Esmaeil, 2012). However, the process of reaching the recommended glycaemic targets for both pre-pregnancy and pregnancy for women with type 1 diabetes, is often difficult, in part reflecting changes in hormones, the requirement for more frequent glucose monitoring and ongoing adjustments to insulin dosage across the pregnancy journey (Soubeiga et al., 2014). This is one of the reasons why self-efficacy, knowledge, good mental health, and social support, are all critical.

Women with type 1 diabetes have described a range of complex and emotionally challenging issues in relation to pregnancy. These can be characterised by desires, anxieties, fears, and uncertainty, in relation to pregnancy, with some negative emotions about pregnancy already present among non-pregnant women with diabetes (McCorry, Hughes, Spence, Holmes, & Harper, 2012). Previous research has consistently highlighted a lack of

knowledge and misconceptions about diabetes and pregnancy among women with diabetes. Perceived self-efficacy for following advice is also important here. Women with type 1 diabetes need to feel confident that they can plan their pregnancies successfully and reach the targets of intensive management that might be recommended during pre-pregnancy counselling. Conversely, if a woman feels she will be unable to achieve these targets, she may avoid seeking pre-pregnancy care. In addition, pre-pregnancy counselling can increase anxiety about pregnancy for some women and they may therefore find it difficult to carry out the desirable health-related behaviours, if they do not possess self-efficacy, optimism and strong support systems (McCorry et al., 2012).

Despite persuasive evidence to attest to the positive impact, attendance by women with type 1 diabetes at pre-pregnancy counselling is persistently low, with most studies considering women in more affluent countries with public health systems, such as Australia, the United Kingdom and Sweden, citing numbers under 30% (Murphy, 2016; Murphy et al., 2017; Murphy et al., 2010a; Murphy et al., 2011; Murphy et al., 2010b). In an Australian study (McElduff et al., 2005) data were collected (on 180 pregnancies from 10 teaching hospitals in NSW, Victoria, and Western Australia) in relation to pregnancy complicated by diabetes, between July 2003 to June 2004. Pre-pregnancy counselling could be documented in only 19.8% of the women: 27.8% with type 1 diabetes and 12% with type 2 diabetes. Folate supplementation at the time of conception was documented in 45.7% of the women: 56.6% with type 1 diabetes, 36.4% with type 2 diabetes (McElduff et al., 2005).

These results are supported by an Australian cross sectional survey of women who attended, or did not attend, pre-pregnancy counselling (Morrison et al., 2018). Women who attended differed by socioeconomic characteristics, being more likely to attend if they were tertiary educated, married or in a de-facto relationship, and employed. This indicates that education, knowledge and health literacy, may be important determinants of pre-pregnancy

counselling attendance. Women with type 1 diabetes were more likely than those with type 2 diabetes to attend pre-pregnancy counselling, perhaps reflecting greater health care awareness in this group. The findings of this study (Morrison et al., 2018) also suggest there is a general lack of awareness among women with type 1 diabetes and type 2 diabetes, in relation to the availability of pre-pregnancy counselling, with almost half of the surveyed women being unaware of services available locally. Despite this, the majority of women (84%) reported they would attend pre-pregnancy counselling if it was available to them, and not surprisingly, the authors recommended that strategies should be implemented to address this issue of awareness (Morrison et al., 2018). These findings suggest that women with type 1 diabetes might be aware of the risks of pregnancy, but not necessarily aware of the importance and availability of specialised pre-pregnancy counselling services. Notwithstanding the fact that pre-pregnancy specialist clinics might not be available in all areas of Australia, increased awareness of the importance and availability of pre-pregnancy counselling is recommended– whether that be via usual health care teams, or specialist clinics.

The Australian National Diabetes Strategy (Australian National Diabetes Strategy 2016-2020) makes specific reference to pre-pregnancy counselling. The strategy outlines Australia's national response to diabetes and also informs how current health care resources can best be managed, coordinated and targeted across all levels of government. This Strategy identifies the most effective and appropriate services and programmes to minimize the impact of diabetes in the Australian community, and lead the way internationally in diabetes prevention, management and research. One of the five primary goals of the strategy is the reduction of the impact of pre-existing and gestational diabetes in pregnancy (Australian National Diabetes Strategy 2016-2020). Potential areas recommended for action include the need to provide accessible pre-pregnancy programmes to women with pre-existing diabetes and those with a history of gestational diabetes, to identify and address factors that may

contribute to adverse outcomes, ensuring that all women with known diabetes receive pre-pregnancy programmes and advice. It is further recommended that it must be ensured that all women with diabetes in pregnancy have access to a credentialled diabetes educator and expert advice relating to diet and physical activity (Australian National Diabetes Strategy 2016-2020).

While women with type 1 diabetes are often experts in their own diabetes management (Griffiths, Lowe, Boardman, Ayre, & Gadsby, 2008; Sparud-Lundin & Berg, 2011), it is clear that they require higher levels of support than usual during pregnancy, from a multi-disciplinary specialist team, trained in the management of type 1 diabetes and pregnancy. Complex and ongoing changes to diabetes management, as well as a focus on reduction of risks to mother and child, require additional support (Paiva, Raposo, & Forbes, 2016). However, whilst women with type 1 diabetes may expect more intensive medical intervention during pregnancy, and can experience reassurance from this, the intense focus on diabetes management also has the potential to detract from the positive experience of pregnancy, leading to reduced mental health and wellbeing (Berg & Sparud-Lundin, 2009; Edwards, Speight, Bridgman, & Skinner, 2016).

The outcomes of a growing body of qualitative studies (Adolfsson, Linden, Sparud-Lundin, Larsson, & Berg, 2014; Berg & Sparud-Lundin, 2009; Linden et al., 2016; Rasmussen et al., 2015; Sparud-Lundin & Berg, 2011) indicate that effective pre-pregnancy counselling requires a balance between presentation of risks, with the experience of the pregnancy itself and the journey to becoming a mother. Mental health and wellbeing may already be affected negatively by living with type 1 diabetes (Fisher, Hessler, Polonsky, & Mullan, 2012; Gonzalez, Fisher, & Polonsky, 2011; Polonsky et al., 1995; Polonsky et al., 2005) and the experiences of pregnancy planning and pregnancy itself, can add pressure and increase emotional distress (Edwards et al., 2016; Langer & Langer, 1998; McGrath & Chrisler, 2017;

Rasmussen et al., 2015; Sparud-Lundin et al., 2011a). Women with type 1 diabetes might experience increased worry and anxiety about pregnancy and their growing baby, as well as concerns about the birth, and motherhood. Up-to-date pregnancy information and adequate support systems are both important in reducing the potential for anxiety and distress around pregnancy, whether in person, or online (Murphy et al., 2010b; O'Higgins, McGuire, Mustafa, & Dunne, 2014; Paiva et al., 2016; Sparud-Lundin & Berg, 2011; Sparud-Lundin et al., 2011a; Sparud-Lundin, Wennergren, Elfvin, & Berg, 2011b; Stenhouse & Letherby, 2011).

As discussed in the following literature review, there are numerous barriers associated with a diminished attendance at pre-pregnancy counselling for women with type 1 diabetes. These include being of a younger age and having had previous pregnancies. Socio-economic factors, living in a rural location, and/or lack of access to specialised pre-pregnancy counselling clinics, are also barriers. Prior negative communication about pregnancy from health care professionals is flagged in numerous studies, as an important factor in women's disengagement from discussions about pregnancy with health care services (Murphy et al., 2010b; Nwolise, Carey, & Shawe, 2016a). It has been suggested, that provision of information about the importance of pre-pregnancy counselling for *every* pregnancy, and an understanding that each woman and each pregnancy is unique, might facilitate increased attendance (Mukona, Munjanja, Zvinavashe, & Stray-Pederson, 2017; Murphy et al., 2010b; Nwolise et al., 2016a). A person-centred approach, positive and open communication, with recognition of the woman's expertise in her own type 1 diabetes management, appear pivotal (Griffiths et al., 2008; King & Wellard, 2009; Meltzer, 2010; Mukona et al., 2017; Murphy et al., 2010b; Nwolise et al., 2016a; Paiva et al., 2016). Importantly, women with type 1 diabetes benefit from support not only from their health care team, but also from their partner and family where appropriate, and other women with type 1 diabetes. This support may occur

across a range of platforms and mediums, including social media, websites and in-person (Adolfsson et al., 2014; Berg, 2005; Berg, Linden, Adolfsson, Sparud Lundin, & Ranerup, 2018; Berg & Sparud-Lundin, 2009; Rasmussen, 2012).

AIMS AND CENTRAL RESEARCH QUESTIONS

This thesis aims to:

1) Better understand the experiences of pregnancy for women with type 1 diabetes, highlighting the time phases of this journey and the key issues during each time phase;

2) Develop a prototype Communication Support Questionnaire for use during Contemplation of pregnancy, to open up conversations about pregnancy and pre-pregnancy counselling, which might enhance this journey; and

3) Examine the qualitative literature in relation to the use of internet-based programmes and resources in delivering pregnancy information and support for women with type 1 diabetes.

Based on the background information presented here, this thesis asks the following questions:

1) What are the time phases and experiences of the pregnancy journey for women with type 1 diabetes? What does this journey look like from the perspective of the women?

2) How can I contribute to the growing body of literature in understanding these experiences?

3) Are there particular phases of the pregnancy journey for women with type 1 diabetes that could be better supported? And what kinds of support would be most useful?

4) Are there common issues for both women and health care professionals across the journey that could be addressed, and how?

5) How can communication about pregnancy and type 1 diabetes be improved between women with type 1 diabetes and health care professionals?

6) How might health care professionals encourage more women to attend pre-pregnancy counselling and be better prepared for pregnancy?

7) Are there particular interventions/resources that might increase women's awareness of the importance of pre-pregnancy counselling and offer more cues to action across the child-bearing years?

8) What is the current evidence for internet-based programmes and resources as a way to deliver information and support to women with type 1 diabetes during pregnancy?

The work responds to these questions firstly through examination of the pregnancy journey for women with type 1 diabetes: specifically, understanding the time phases and the experiences women might have. The outcome from this is the development of a theoretically driven model of the journey of pregnancy for women with type 1 diabetes, highlighting the Contemplation phase of pregnancy as being a key time to focus on, and that pre-pregnancy counselling is a critical factor to improved pregnancy outcomes. This leads to the development of a prototype Contemplating Pregnancy in Diabetes Communication Support Questionnaire in phase 2 of the work. This is aimed at supporting communication about pregnancy between health care professionals and women with type 1 diabetes who are considering pregnancy in the next 1-5 years. This prototype Questionnaire aims to understand women's knowledge of, and the importance placed on, the desirable health related behaviours for pregnancy with diabetes; and the personal, social and psychological resources the woman has available for the journey. The prototype Questionnaire is now finalised so that further work can be conducted. Finally, in study three, I present a meta-synthesis of the qualitative literature, in relation to the use of the internet-based programmes and resources, in supporting the pregnancy journey for women with type 1 diabetes. This thesis has been informed by the social cognition models, of which the Health Belief Model is one. This is discussed further in chapter 2.

ABOUT THE RESEARCHER - REFLEXIVITY

In working with people and understanding their lives, methodological issues arise as part of the research design. In particular, questions about subjectivity and intersections between participant's and researcher's lives, the research process, and the intended and unintended outcomes of research, need to be understood and examined (Finlay, 2002). The perspective and prior experiences of the researcher will guide their research and a researcher's personal experiences will influence what they choose to investigate, the methods they select for this purpose, the findings they believe are the most important to report, and how they report on their results and conclusions (Schmid, 1981). As a researcher, I have had to manoeuvre between three positions. In one position I am the researcher; in the second position I am a health care professional who has worked in diabetes for many years; and in the third position, I am a woman with long-standing type 1 diabetes (since 1979) who has experienced 4 pregnancies, and has 3 children. I have identified with numerous women with type 1 diabetes over many years as part of the online diabetes community, and as a key health care professional delivering mental health services to people with diabetes.

This means I must continually strive to not allow my personal and professional positions to influence my research, or to at least be aware of my position. Reflexivity is critical due to my personal history and professional experiences. I was told at 12 years old that I would never have babies and if I did, they would be born dead or deformed. Through my practice in diabetes counselling over many years I discovered other women who were told comparable 'facts'. I worked in diabetes and mental health from 2001 – 2016, after founding Diabetes Counselling Online. The counselling records used in the first study were from the archives of this service. I recognise these experiences have led me to choose this research topic and are likely to affect the way I investigate, view and present the findings. These experiences potentially affect both my subjectivity and my positionality in the research.

Positionality is the relational place or value the researcher holds, which influences and is influenced by varying contexts. For example, the social, political, historical, educational, and economical contexts, to name a few. Understanding positionality is critical in analysing the subjectivity of researchers (Finlay, 2002). Subjectivity, relates to the life experiences a researcher has had and the social, cultural, and political factors that influence them, and how these experiences and factors contribute to biases and assumptions in the type of research that researchers choose to engage in (Finlay, 2002). In addition, subjectivity may impact on how a researcher chooses to interpret and analyse their research. The response of participants to the calls for the pilot study in the second study of this research might have been affected by my positionality, in that women who responded might have already held an awareness of my personal experience of type 1 diabetes and pregnancy, as well as my role in the diabetes community. If so, this would almost certainly have affected their likelihood of participating, and potentially, their responses. Holding awareness of my subjectivity and positionality was important in the research process. In developing this work, I asked myself a series of questions about my personal experiences in relation to pregnancy, which had been very emotional. As a young girl, I had wanted to be a mother in the future, prior to developing type 1 diabetes. After my traumatic experiences as a child in relation to pregnancy information, I hold very personal and emotive memories. Along with this, my experience of the pregnancy journey was deeply affected by my own type 1 diabetes and interactions with many other women over the past 16 years.

When the researcher has a deep personal experience of the topic such as in this case, a systematic approach and openness to finding the unexpected, as well as being clear about the potential impact of the researcher on this process, is important at every step of the process (Krefting, 1991). Peer examination assists in this process and requires the researcher to discuss the research process and findings with impartial colleagues, who have experience

with research methods. The findings are discussed as a team and any issues brought up as a way of working through these (Krefting, 1991). During the qualitative process, colleagues in particular, can increase credibility of the findings by checking codes and themes developed through the data, and ensure that mutual understanding is reached, with an impartial approach. In addition, peer examination offers an opportunity for the researcher to present their working hypotheses, which can then be discussed and developed, in the continuing design of the study (Krefting, 1991). In this work I was able to review my position in the research regularly via supervision. In particular, during the thematic analysis in chapter 3, there was a rigorous process of checking and re-checking emerging themes across the supervision team, to ensure agreement. In the meta-analysis in chapter 5, my primary supervisor independently assessed 2 of the papers in the study, to determine if the findings mapped onto the categories I had developed and we engaged in discussion to ensure these were agreed upon, before finalisation of the chapter.

BACKGROUND

More than 275 people are being diagnosed with type 2 diabetes in Australia per day, reflecting increasing rates of obesity and longevity. The rate of type 1 diabetes is also growing for unknown reasons (NDSS, 2017). There were 1,240,151 people registered as having diabetes on the National Diabetes Services Scheme (NDSS) register as at 31/3/17 – with 10% of these having type 1 diabetes (NDSS, 2017). The proportion of pregnancies in Australia affected by diabetes is increasing, primarily due to increases in type 2 diabetes related to obesity and later childbearing (Abell, Nankervis, Khan, & Teede, 2016).

Diabetes is one of the leading causes of blindness, kidney disease, heart attack and stroke ("Diabetes Australia: Preventing Complications," 2015). Young children, teens, pregnant women, the elderly and those with co-existing chronic conditions, may have specific problems. Serious physical and mental health complications associated with all types of diabetes, include lower limb amputations, kidney failure, visual impairment and blindness, depression, neuropathy, stroke and early death ("Diabetes Australia: Preventing Complications," 2015).

As used in the Diabetes Control and Complications Trial (DCCT), a landmark study which recruited its first participants in 1983 (Nathan, 2014), the ‘gold standard’ for glycaemic assessment in diabetes, is the glycosylated haemoglobin A1c (HbA1c or A1c) . The investigators in the DCCT reported that intensive glycaemic management for people with type 1 diabetes was far superior to conventional therapy, for the prevention of microvascular (retinopathy, neuropathy, nephropathy) complications, as well as the risk of progression of these complications (Nathan, 2014). A target of 7% (53mmol/mol) HbA1c is generally recommended, although this should be individualised and is lower for pregnancy. A major limitation of many strategies to achieve tight glycaemic management, is the increased risk of hypoglycaemia, which is hazardous and can impact negatively on quality of life (ADS, 2009).

TYPES OF DIABETES

There are 3 main types of diabetes, which may all impact a pregnancy – type 1, type 2 and gestational diabetes. Women with gestational diabetes, occurring only during pregnancy, will have different issues to those with pre-existing diabetes during pregnancy. All of these types of diabetes may affect pregnancy, but will present with varying difficulties and complications and are distinct conditions, with different management strategies. In this thesis I have chosen to focus on type 1 diabetes, which is explained further in the following sections. I will outline the different types of diabetes here first.

Type 1 diabetes

Type 1 diabetes is an autoimmune disease. While type 1 diabetes can occur at any age, it is the most common form of diabetes diagnosed under 30 years of age, often first presenting in childhood. Some women are diagnosed with type 1 diabetes during or after pregnancy, because it may be the first time they have had contact with a health professional in relation to their blood glucose levels (DCSM, 2017). It is theorised that environmental factors trigger the process of autoimmunity in an already predisposed person ("What Is Type 1 Diabetes - JDRF Australia," 2017). Once the body's immune system begins attacking the insulin producing beta cells of the pancreas, it can take from a few weeks to many years for the vast majority of the beta cells to be destroyed. In the longer term, persistent high blood glucose levels may lead to a range of complications including damage to major organs and nerves throughout the body, heart attack, stroke and early death. There is currently no prevention or cure for type 1 diabetes. Whilst small numbers of islet cell and pancreatic transplant procedures are being trialled for people with type 1 diabetes, these are not widespread options and bring their own health risks (DCSM, 2017; "Type 1 diabetes," 2017a; "Diabetes mellitus type 1 - Wikipedia," 2017; NDSS, 2015; "Type 1 diabetes," 2017b; "What Is Type 1 Diabetes - JDRF Australia," 2017).

Regular blood glucose monitoring, monitoring of carbohydrate intake, and either insulin injections or a continuous subcutaneous insulin infusion (CSII) pump, are the standard tools for management, with support from a health care team qualified in diabetes care. Mental health can be affected adversely by the ongoing demands of management, which have been described appropriately, as relentless (El Achhab, Nejjari, Chikri, & Lyoussi, 2008; Fisher, Glasgow, Mullan, Skaff, & Polonsky, 2008; Fisher et al., 2012; Kreider, 2017; Polonsky et al., 2005).

Type 2 diabetes

Type 2 diabetes has strong genetic and family related risk factors and accounts for about 85–90 per cent of all cases of diabetes, usually developing in adults over the age of 45 years. However, its incidence is rising in younger age groups including children, adolescents and young adults, so that more women of child bearing age have type 2 diabetes before pregnancy (DA, 2017b; DCSM, 2017). Type 2 diabetes is a progressive metabolic condition where the person's body becomes resistant to insulin, often due to obesity, and/or their pancreas loses the capacity to produce sufficient insulin to regulate blood glucose (DA, 2017b; DCSM, 2017). Type 2 diabetes is both a disease entity and a risk factor for other disease, predominantly cardiovascular and cerebrovascular disease (Colagiuri S, Davies D, Girgis S, & R, 2009.). It is strongly associated with modifiable lifestyle risk factors, which means that it can be prevented, or at a minimum, delayed, if diagnosed early enough, through healthy lifestyle changes (DA, 2017b).

There are a number of risk factors for type 2 diabetes, including family history of type 2 diabetes, or being from particular ethnic backgrounds, for example Aboriginal and Torres Strait Islander Peoples'. For some people, the first evidence of type 2 diabetes may be a complication of diabetes such as a heart attack, vision problems or a foot ulcer. The Australian Diabetes Society recommends individualised HbA1c targets for all people with

diabetes, taking into consideration the presence of cardiovascular disease, diabetes duration, diabetes medication(s) used, comorbidities, and problems with hypoglycaemia (ADS, 2009). Type 2 diabetes is often initially managed with a combination of regular physical activity, healthy eating and weight reduction. As type 2 diabetes is usually progressive, most people will need pharmacotherapy such as oral medications and/or insulin injections in addition to lifestyle changes over time. Options for management have changed substantially for type 2 diabetes over the past decade, with the development of new drugs and more awareness of the importance of lifestyle changes in its prevention (DA, 2017b).

Gestational Diabetes

Whilst not a focus of this work, it is important to understand gestational diabetes, which occurs only in pregnancy. Gestational diabetes (sometimes referred to as GDM) is a form of diabetes that occurs during pregnancy and usually resolves after the baby is born (DA, 2017a). It is diagnosed when higher than usual blood glucose levels are first evident during pregnancy. Women with gestational diabetes do have a much higher risk of future type 2 diabetes, and to have subsequent pregnancies affected by diabetes. Gestational diabetes is the fastest growing type of diabetes in Australia, affecting thousands of pregnant women each year. In part this reflects the lower thresholds now advocated for the diagnosis of dysglycemia during pregnancy (DA, 2017a).

Between 5% and 10% of pregnant women will develop gestational diabetes and this usually occurs around the 24th to 28th week of pregnancy. Most women are tested for gestational diabetes as part of the 24-28-week routine examination. The usual physiological changes during pregnancy result in a diabetogenic state for the growth and wellbeing of the baby and GDM is likely related to a combination of this and other factors (minor pre-existing insulin resistance or other.) Hence why GDM most often resolves after pregnancy. These changes are also what make pregnancy challenging for women with type 1 and type 2 diabetes.

Women who have one or more of the risk factors for GDM are advised to have an oral glucose test or challenge, when pregnancy is confirmed, then again at 24 weeks if diabetes was not detected in early pregnancy (DA, 2017a).

PHYSICAL AND MENTAL IMPACTS OF DIABETES

Diabetes is a complex chronic condition that affects the way in which the body processes glucose and is associated with so called "microvascular' (eyes, kidneys, nerve damage), and 'macrovascular' (heart attack, stroke) complications, as well as psychological conditions. The complications of diabetes are the same for type 1 and type 2 diabetes ("Diabetes Australia: Preventing Complications," 2015). As well as the risks for physical complications, living with diabetes frequently impacts on quality of life and psychological wellbeing (Polonsky et al., 2005).

There is a large body of literature to indicate that depression is more common in people with diabetes than the general population. It is associated with chronic hyperglycaemia and increased risk for both diabetes complications, and mortality (Gonzalez et al., 2011). Type 1 diabetes self-management, in particular, has been described as requiring a complex, demanding, and often confusing set of self-care activities. As a result, people can become frustrated, angry, overwhelmed, and/or discouraged (Polonsky et al., 2005). Living with diabetes has also been shown to affect family members and might lead to conflict with loved ones. Relationships with health care providers may become difficult (Polonsky et al., 2005). The increased risks for depression may result in a reduction in motivation for self-care (Kreider, 2017; Polonsky et al., 2005).

Due to the need for daily self-management tasks, the risks of diabetes complications, and the difficulties associated with managing a very complex disease, 'diabetes specific distress' occurs frequently (Fisher et al., 2012). Diabetes specific distress relates to issues pertaining only to diabetes, including fear of hypoglycaemia, anxiety about diabetes complications,

distress about a lack of spontaneity in life and social barriers related to diabetes. These can all lead to diabetes burnout and major emotional distress (Anderson, Freedland, Clouse, & Lustman, 2001; Dalfra, Nicolucci, Bisson, Bonsembiante, & Lapolla, 2012; de Groot, Anderson, Freedland, Clouse, & Lustman, 2001; Do et al., 2017; Fisher et al., 2008; Goldney, Phillips, Fisher, & Wilson, 2004; Gonzalez et al., 2011; Katon, Russo, Gavin, Melville, & Katon, 2011; Polonsky et al., 1995)

TYPE 1 DIABETES AND PREGNANCY

Given the evidence presented that women with type 1 diabetes have the highest rates of complications and adverse outcomes during pregnancy, and the fact that the 3 types of diabetes are distinct from each other, this thesis focusses on type 1 diabetes and pregnancy. Type 1 diabetes is associated with numerous risks and complications of pregnancy, including twice the risk of congenital malformation, three times increased risk of death of the baby and a five times increased risk of stillbirth, premature birth and being large for gestational age. Increased maternal risks include miscarriage, pre-eclampsia and premature birth (Colstrup et al., 2013; Egan et al., 2017c; Hughes, Spence, Holmes, & McCorry, 2010; Inkster et al., 2009). Type 1 diabetes and maternal hyperglycaemia during the first 8 weeks of pregnancy have a detrimental effect on the foetal heart, renal, musculoskeletal and central nervous system (Abell, Nankervis, Khan, & Teede, 2016). Population based studies (Maresh et al., 2015; Pearson et al., 2007) are indicative of a five-times increase in the rate of cardiovascular malformations and more than twice the rates of neural tube defects and urinary tract abnormalities in babies of women with type 1 diabetes, compared to women without diabetes. Congenital malformations are associated with increased risks of stillbirth and perinatal mortality, accounting for almost 50% of all deaths of babies being born to mothers with type 1 diabetes (Meltzer, 2010; Pearson et al., 2007; Wahabi et al., 2012).

Preeclampsia occurs more often in women with type 1 diabetes than in other women and rates of elective caesarean section are greater than for women without diabetes, with emergency caesarean sections also being increased (Owens, Sedar, Carmody, & Dunne, 2015). Maternal morbidity for women with type 1 diabetes is double that of women without diabetes (Owens et al., 2015). Babies are also more likely to be born prematurely and neonatal hypoglycaemia occurs more in babies of women with type 1 diabetes, which contributes to the higher rate of admission to neonatal intensive care (Owens et al., 2015).

The Australasian Diabetes in Pregnancy Society (ADIPS) Position Statement on Management of Pregnancy in Diabetes includes recommendations that information and counselling be provided to all women of reproductive age with type 1 diabetes. This is to increase awareness of the problems that may arise during pregnancy, the potential dangers inherent in unplanned pregnancy, and the benefits of pre-pregnancy counselling ("ADIPS Consensus Guidelines for the Testing and Diagnosis of Hyperglycaemia in Pregnancy in Australia and New Zealand | Australian Clinical Practice Guidelines," 2015; McElduff et al., 2005).

ADIPS recommend that women with type 1 diabetes undergo more intensive medical tests than women without diabetes during pregnancy. These include a first trimester nuchal translucency (possibly with first trimester biochemical screening with pregnancy-associated plasma protein A and beta-human chorionic gonadotropin); that ultrasound needs to occur for foetal morphology at 18-20 weeks, if required, for cardiac views at 24 weeks and for foetal growth at 28-30 and 34-36 weeks. Induction of labour or operative delivery is recommended to be based on obstetric and/or foetal indications (McElduff et al., 2005). The Australian Diabetes Society (ADS) states that level 3 neonatal nursing facilities may be required following birth and that this should be anticipated when birth occurs before 36 weeks, or where there have been difficulties with glycaemic control during pregnancy. Insulin

requirements rise greatly across the pregnancy and fall rapidly during labour and in the puerperium. At this time, close monitoring and adjustment of insulin doses is necessary (McElduff et al., 2005). ADIPS further recommend issues relating to pregnancy are discussed at each annual diabetes review, and more frequently if required ("ADIPS Consensus Guidelines for the Testing and Diagnosis of Hyperglycaemia in Pregnancy in Australia and New Zealand | Australian Clinical Practice Guidelines," 2015; Craig ME et al., 2011; "Diabetes | APEG," 2017; McElduff et al., 2005).

Pregnancy for women with type 1 diabetes is often overshadowed by the requirement to achieve optimal glycaemic control, which has the potential to increase emotional distress and the risk of severe hypoglycaemia (Sparud-Lundin & Berg, 2011). This in itself, can increase anxiety (Sparud-Lundin & Berg, 2011). Evidence derived from a number of qualitative studies and literature reviews (Berg, 2005; Berg & Honkasalo, 2000; Berg & Sparud-Lundin, 2009; Linden et al., 2016; Rasmussen, 2012; Rasmussen et al., 2015; Sparud-Lundin & Berg, 2011; Sparud-Lundin et al., 2011a) suggests that in general, pregnant women with type 1 diabetes experience a higher degree of anxiety, worry, pressure and ambivalence about pregnancy outcomes, compared to women without diabetes.

FOCUS FOR THIS WORK

TYPE 1 DIABETES AND PRE-PREGNANCY COUNSELLING

Pre-pregnancy counselling includes diabetes care specifically targeted at optimising diabetes management prior to conception (Morrison et al., 2018). It is suggested that this includes motivational counselling, healthy lifestyle, glycaemic management, and appropriate pharmacologic therapy. There is a growing literature (Egan, 2015; Murphy et al., 2010b; Nwolise, Carey, & Shawe, 2016b; Owens et al., 2016; Zhu, Graham, Teh, & Hornbuckle, 2012) to indicate that pre-pregnancy counselling has the potential to increase the likelihood

of a healthy pregnancy and baby for women with type 1 diabetes substantially. However, there is variation in outcomes from prior studies, which warrants further investigation.

Pre-pregnancy counselling usually includes regular review by a multidisciplinary diabetes team, in a dedicated outpatient clinic (Egan et al., 2017d). However, there is no consensus as to the format for delivery of this care. While many groups have reported positive benefits associated with their own pre-pregnancy counselling services and clinics, the outcomes reported are varied (Egan et al., 2017d). Therefore, this thesis has chosen to explore pre-pregnancy counselling further and to develop tools to assist in the process.

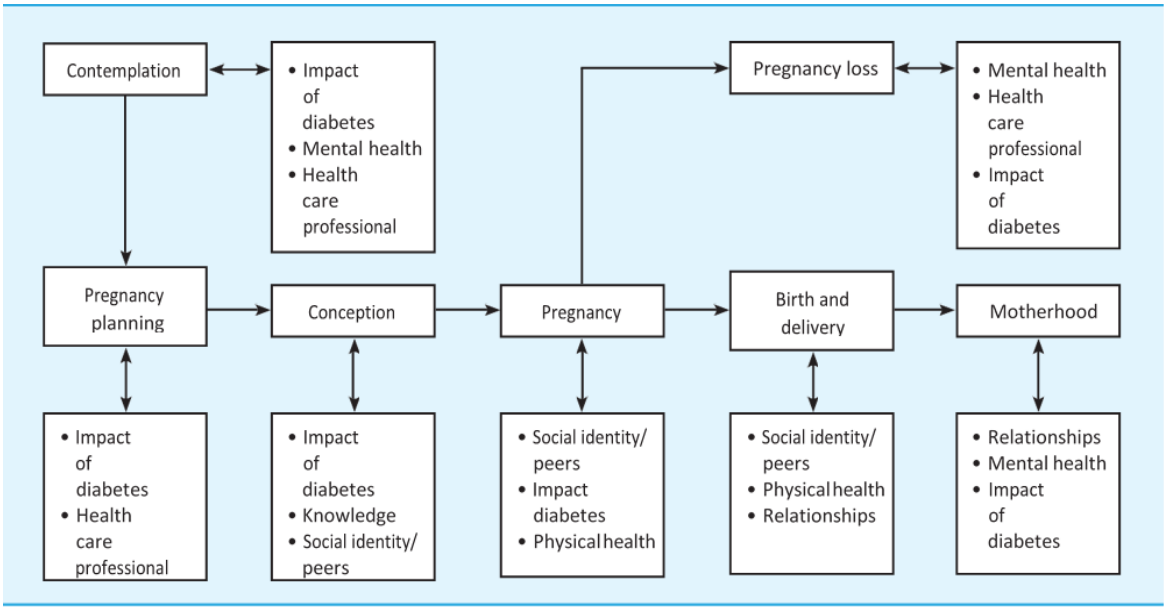
A number of bodies internationally recommend pre-pregnancy counselling be delivered by a multi-disciplinary team, be relevant, timely, and balanced, and provide up-to-date information and an overall positive message (Abell et al., 2016; Colstrup et al., 2013; Egan, Danyliv, Carmody, Kirwan, & Dunne, 2016). What is clear, is that a supportive and encouraging relationship between women with type 1 diabetes and their health care professionals, is more likely to lead to women attending pre-pregnancy counselling when they wish to plan a pregnancy (Murphy et al., 2010a; Murphy et al., 2010b; Temple, 2011).

I have chosen to focus on type 1 diabetes in this work, because of the complex issues associated with its management during pregnancy and propensity for adverse outcomes. Many of the issues related to preparation for pregnancy and management of diabetes during pregnancy in type 1 diabetes, are distinct, as compared to type 2 diabetes and gestational diabetes.

THE 'JOURNEY' OF PREGNANCY FOR WOMEN WITH TYPE 1 DIABETES

The concept of the 'pregnancy journey' discussed in this thesis, pertains to the model shown below, which I developed in chapter 3 of the work. This journey relates to the time-phases women with type 1 diabetes might experience across pregnancy.

MODEL OF THE JOURNEY OF PREGNANCY FOR WOMEN WITH TYPE 1 DIABETES DEVELOPED DURING STUDY 1



Contributing to the body of knowledge in the field of diabetes and pregnancy, these time-phases are presented in detail in chapter 3, where the thematic analysis established that they are all discrete points at which to consider interventions and support for women with type 1 diabetes. Whilst similar to the time phases of pregnancy for women without type 1 diabetes, there are unique themes and issues that arise at each point (Edwards et al., 2016). The Contemplation phase is central to this thesis. Because it is recommended that women with type 1 diabetes attend pre-pregnancy counselling and that they require a higher than usual level of preparedness for pregnancy, the phase of Contemplation is highlighted as being the starting point for pregnancy preparation, rather than the point of pregnancy planning. It is suggested that this period of Contemplation might last for many years. It is also suggested that more internet-based programmes and resources related to pregnancy and diabetes, should

be developed and researched, allowing women with type 1 diabetes to seek information and support across their child-bearing years themselves.

LITERATURE REVIEW

There were 3 points at which I conducted a literature review for this work. Initially, prior to beginning of my PhD, I conducted an in-depth review to ascertain the focus for the work. This was repeated, as part of study 2 to inform the study 2, and finally refined for the meta-synthesis. This section presents the key themes and gaps from these reviews, which are relevant to the research aims and outcomes. The literature reviews identified gaps in knowledge and issues requiring further research. This included gaining deeper understanding of pregnancy experiences for women with type 1 diabetes; how to ensure provision of cues across a woman's child-bearing years in relation to pregnancy preparation; and how to improve communication about pregnancy between women with type 1 diabetes and their health care professionals, in particular with a focus on internet-based programmes and resources. These understandings led to development of the final research questions, and, consequently, the research framework being developed.

PROVISION OF PREGNANCY INFORMATION

Whilst preparation for pregnancy has been shown to be a major factor in improved outcomes for women with 1 diabetes, some women, irrespective of the presence of diabetes, will become pregnant without planning (Griffiths et al., 2008). Therefore, rather than considering either an unplanned *or* planned pregnancy, it is suggested that it may be more appropriate to consider a continuum of planned *to* unplanned, with all women of child-bearing age being seen as 'potentially pregnant' and, therefore, being in the Contemplation phase of pregnancy over an extended period of time (Griffiths et al., 2008). Pre-pregnancy services and pregnancy information related to type 1 diabetes, should thus be tailored to the changing needs and situation of each woman, and each pregnancy (Griffiths et al., 2008).

Pregnancy information, in particular the importance of pre-pregnancy counselling and preparation, is recommended to be available across a broad range of platforms, including at regular doctor appointments and clinics, via websites and social media - and be offered at regular intervals across the child bearing years - not just during pregnancy planning (Benute et al., 2010; Endres et al., 2004; Griffiths et al., 2008). It is repeatedly suggested in the literature, that if pregnancy information does not offer positive encouragement about becoming and being a mother alongside information about the risks, it may well increase the propensity for women with type 1 diabetes to experience distress and increase rates of disengagement from health care services (Berg, Adolfsson, Ranerup, & Sparud-Lundin, 2013; Berg et al., 2018; Berg & Sparud-Lundin, 2009; Linden, Berg, Adolfsson, & Sparud-Lundin, 2017; Linden et al., 2016; Rasmussen et al., 2015; Sparud-Lundin & Berg, 2011).

A semi-structured interview study (Murphy et al., 2010b) concluded that more integrated diabetes and reproductive health⁄contraceptive advice is required; that women need to appreciate the time between ceasing contraception and conception may be short; and that all women with all types of diabetes, particularly those in whom outcomes of prior pregnancies have been negative, require better support *between* pregnancies. The authors conclude that more research is needed as to how communication between health professionals and women with diabetes across the child-bearing years can be improved (Murphy, 2010). Further, information about pre-pregnancy counselling, provided in a positive and balanced manner, is clearly required to be developed and offered in more creative ways. These findings underpin the focus of this thesis.

MENTAL HEALTH AND WELLBEING DURING PREGNANCY

There are numerous studies reporting on the medical outcomes of pregnancy in type 1 diabetes. However, few have examined the mental health and wellbeing of women with type 1 diabetes across the pregnancy journey (Lavender et al., 2010). Perceptions about pregnancy

and expectations in relation to the likelihood of a healthy baby, can impact on wellbeing and behaviours for women with type 1 diabetes, both during and after pregnancy (Lawrence, 2011). These perceptions and expectations have been found to be influenced by diabetes type, race/ethnicity, social class, number of pregnancies, age and access to specialty health care (Lawrence, 2011). Some of the current evidence in the literature suggests that women with type 1 diabetes have a higher risk of depression than women without diabetes (Kozhimannil, Pereira, & Harlow, 2009). However, as shown below, these observations are inconsistent.

A retrospective cohort study of low-income mothers with diabetes (all types) (Kozhimannil et al., 2009) reported that after adjusting for age, race, year of delivery and gestational age at birth, women with diabetes had nearly double the odds of experiencing post-natal depression. Women with diabetes and no pre-natal indication for depression, had a higher prevalence than women without diabetes, of receiving a diagnosis of post-natal depression, and/or of taking antidepressant medication in the year following birth. Type 1 diabetes and gestational diabetes, were both independently associated with peri-natal depression, including new onset of post-natal depression, with an approximate doubling of the risk (Kozhimannil et al., 2009).

While this evidence is consistent with the background increased risk of depression in diabetes (Anderson et al., 2001; Gonzalez et al., 2011; Lustman et al., 2000; Polonsky et al., 1995) the authors were unable to determine whether the association between diabetes and peri-natal depression was causal. Furthermore, given that there was no information provided about personal or familial history of depression, weight or body mass index, or neonatal complications, these were not controlled for in the analyses. By flagging medication use as an additional marker for depression, the authors stated there was potential to lead to an overestimate of the prevalence of depression in the women in their study (Kozhimannil et al., 2009).

In a cross-sectional analysis of baseline data from a prospective cohort study of pregnant women receiving pre-natal care (Katon et al., 2011) women with type 1 diabetes had 54% greater risk of any antenatal depression when compared to those without diabetes. However, after adjusting for important covariates the association was attenuated (OR 1.16, 95% CI 0.79-1.71). Results were similar for the risk for antenatal major depression. In contrast to Kozhimannil et al, they concluded that neither type 1 diabetes nor gestational diabetes were independently associated with an increased risk of antenatal depression, but rather that the presence of chronic disease, and the burden of the co-morbidities of disease, may increase the risk. Finally, they concluded that although diabetes itself may not independently increase the risk of antenatal depression, the presence of one or more chronic medical conditions increased this risk significantly, highlighting the importance of screening for depression among pregnant women with chronic medical conditions, including diabetes (Katon et al., 2011).

A semi-structured interview study of 326 pregnant women with a 'medical disorder' using the Primary Care Evaluation of Mental Disorders (PRIME-MD) scale (Benute et al., 2010) included women with diabetes (n=84). All women were interviewed at a mean gestational age of 28.2 weeks. Major depressive disorder was diagnosed in 29 cases (9%). In women with diabetes (any type) the rate of diagnosis of major depressive disorder was 7.1%, the same as pre-eclampsia and chronic hypertension; whereas the prevalence was 12% for heart disease, 6.3% for anaemia, 8.3% for colleganosis and 12.5% for risk of preterm delivery. The limitations of this study included the variety of medical conditions that were included and the failure to specify diabetes type. Moreover, no measure specific to diabetes distress was used and the psychiatric diagnoses were only made at one-time point during the pregnancy and it was, therefore, unclear whether these symptoms may have been transient (Benute et al., 2010). What this study did establish was that unplanned pregnancy was associated with the

diagnosis of depression for these women with chronic conditions, including diabetes. This is relevant to the presentation of evidence in this thesis, i.e. that providing information about pre-pregnancy counselling earlier to women with type 1 diabetes and supporting them towards increased preparedness for pregnancy, might assist with improved mental health and wellbeing.

DEPRESSION VS DIABETES DISTRESS DURING PREGNANCY FOR WOMEN WITH TYPE 1 DIABETES

Despite inconsistencies, depression and diabetes distress have been shown in the small body of qualitative literature, to be important factors during pregnancy for women with type 1 diabetes. However, it is difficult to make conclusions because general depression and anxiety measures have been used in almost every prior study in relation to diabetes and pregnancy. This is problematic because there is growing evidence that whilst diabetes specific distress and depression might exist alongside each other, they are distinct issues with specific interventions. Therefore, diabetes specific distress measures are needed in pregnancy and type 1 diabetes research and in practice, to extrapolate the issues of depression vs distress (Fisher et al., 2007).

As well as the increased risk of depression in the background diabetes population, there is evidence that approximately one-fifth of all women (in the general population) present with depression during pregnancy and puerperium, and almost 13% of pregnant women experience a major depressive disorder (Lusskin, Pundiak, & Habib, 2007). Accordingly, depression is more common in pregnancy and early motherhood than previously thought, and there is no predictable protective effect of pregnancy. Moreover, relapse rates are high and there is a higher potential for depression in the post-natal period. It has been suggested that early identification and treatment of peri-natal depression, may lower the risks of morbidity for the woman, her child and her family (Lusskin et al., 2007).

Given the already higher risk of depression and distress for people with diabetes, coupled with this reported increased risk of depression in the post-natal period, it is important to consider mental health and support systems for women with type 1 diabetes, prior to entering into pregnancy. I propose that given the evidence, preparedness includes not only the physical and medical management of diabetes and pregnancy, but the personal, social and psychological resources needed for the journey. Understanding diabetes specific distress and how this may present during pregnancy, as well as separating this from depression is important, because these issues require different interventions and management (Fisher et al., 2008; Fisher et al., 2012; Goldney et al., 2004; Gonzalez et al., 2011; Polonsky et al., 2005).

A survey study of quality of life in pregnancy and post-partum in women with diabetes (Dalfra et al., 2012) found that pregnancy was associated with a perception of poor general health in both women with type 1 diabetes and gestational diabetes. After the birth of their baby, whilst significantly worse depressive symptoms were documented in both groups, worse physical and psychological wellbeing was only identified in women with type 1 diabetes. The authors concluded that women with type 1 diabetes, irrespective of how long they had lived with the condition, found it difficult to accept their diabetes, particularly considering it a serious disease that may impact on the outcome of their pregnancy (Dalfra et al., 2012). It was suggested that wellbeing in women with type 1 diabetes may have decreased following the birth of their baby, potentially reflecting the outcome of fluctuations in blood glucose levels, combined with worry about their capacity to cope with their new situation as mothers, including care of their baby (Dalfra et al., 2012). This study provides evidence that diabetes related distress increases following the birth and emphasises the importance of considering the emotional profile of women with type 1 diabetes before entering into pregnancy and motherhood.

THE IMPORTANCE OF SOCIAL SUPPORT

There is evidence that appropriate and adequate social support across the journey of pregnancy is fundamental to improved outcomes for women with type 1 diabetes and their babies. In particular, connection with other women with diabetes is reported in a number of studies as being beneficial (Berg & Sparud-Lundin, 2009). This includes early and ongoing support from a healthcare team who share positive messages about pregnancy, alongside the risks, and who utilise new technologies for management of type 1 diabetes during pregnancy. Inclusion of partner and family members in pre-pregnancy counselling, in particular the woman's mother where appropriate, appears to be useful (Berg, 2005; Berg & Honkasalo, 2000; Collier et al., 2011; Dalfra et al., 2012; King & Wellard, 2009; Lavender et al., 2010; Lawrence, 2011; Linden et al., 2016).

In Contemplation of pregnancy, the kind of support offered to women with type 1 diabetes might impact their attendance at pre-pregnancy counselling. This includes women being more likely to attend if referred directly by a healthcare professional they know, such as a General Practitioner (Griffiths et al., 2008). However, sometimes the information about pregnancy provided by health care professionals can increase a woman's concerns, because it is either not accurate, is discouraging, or offers only pessimistic outcomes (Rasmussen, 2012). Worryingly, it has been reported that some women are not receiving *any* information about the importance of pre-pregnancy counselling (Berg & Sparud-Lundin, 2009; Dalfra et al., 2012; King & Wellard, 2009). On the other hand, women who are supported and encouraged about pregnancy by their health care team, tend to be more satisfied with their experiences and have fewer negative emotions (King & Wellard, 2009; Levy-Shiff, Lerman, Har-Even, & Hod, 2002).

Women with type 1 diabetes are reported to rely on specific health care professionals for support in planning and managing pregnancy. These are usually those health care

professionals they trust and have a prior relationship with, often being general practitioners and diabetes specialists (Griffiths et al., 2008). Midwives are ideally positioned to provide pre-pregnancy counselling to women with type 1 diabetes and could be an important link in terms of pre-pregnancy advice for women with type 1 diabetes (Hughes et al., 2010). By embracing their role as health promoters, midwives could be pivotal in pre-pregnancy counselling and follow-up after pregnancy, particularly within community settings, by raising awareness among women with type 1 diabetes and other health care workers who are in regular contact with women with diabetes, about the importance of pre-pregnancy counselling (McCorry et al., 2012).

When women are offered a variety of support in planning and managing pregnancy, their self-confidence and self-efficacy are increased (Griffiths et al., 2008). Shared decision making and a positive and empowering approach is therefore required (Griffiths et al., 2008; Murphy et al., 2010b). Both the woman and her family, where appropriate, should be consulted and included in all decision making around the pregnancy and the birth experience (Stenhouse & Letherby, 2011).

SHARED DECISION MAKING AND PERSON-CENTRED CARE: THE IMPORTANCE OF COMMUNICATION

It has been estimated that a person with type 1 diabetes spends just 3 hours each year with their health care professional. For the remainder of the time they are managing their own condition (Chatterjee, Davies, Stribling, Farooqi, & Khunti, 2018). This short duration of time available could potentially compromise the provision of pregnancy information, when there are competing educational and diabetes management issues that need to be addressed in consultations. Effective communication skills are, therefore, critical.

The relationship between health care professionals and women with type 1 diabetes and their style of communication, have been shown to be important, in particular as it relates to

planning for pregnancy and pre-pregnancy counselling (Berg & Sparud-Lundin, 2009). It is suggested in a number of studies, that the role of the health care professional is to offer knowledge and expertise to support the woman to make informed decisions, but that it is the woman who will need to make the daily diabetes management decisions and choices during the pregnancy journey (Alzaid, 2014). Shared decision making and person-centred care are, therefore, very important aspects of the relationship between women with type 1 diabetes and their health care professionals.

Shared decision making has been described as being at the very centre of person-centred care (Thompson-Leduc, Clayman, Turcotte, & Legare, 2015). Shared decision making is defined as a process – 'undertaken jointly between a patient and their clinician, in which best clinical evidence is considered, in the light of patient-specific characteristics and values' (Thompson-Leduc et al., 2015). This means that true shared-decision making must be individualised and relevant to each person's life and unique circumstances.

Supporting the need for shared-decision making and positive communication, a small qualitative study (Collier et al., 2011) considering perceived barriers to management of diabetes during pregnancy, described knowledge, attitudes and behaviours among pregnant women with pre-gestational (type 1 and type 2) and gestational diabetes. Focus groups were held with women who had recently been pregnant, nine with women with gestational diabetes and seven with women who had pre-gestational diabetes. They described participants as identifying five main barriers to management of diabetes during pregnancy. These were financial barriers and difficulties accessing care; maintaining a healthy diet and exercising; communication difficulties; lack of social support; and barriers related specifically to diabetes care. The women in the study with pre-gestational diabetes expressed concern about the increased risk of adverse outcomes for their babies. The majority were aware of the importance of achieving excellent glycaemic control both before and during the pregnancy.

However, low rates of pregnancy planning were reported and pregnancy planning was not identified as a strategy to ensure a healthy baby. This study also reports that pre-pregnancy counselling has to potential to be unhelpful and disregarded by women, if occurring at a time that is not relevant to her, and she is not considering pregnancy in the near future (Collier et al., 2011).

In relation to communication style, an explorative and descriptive study of antenatal consultations between midwives and their clients at four antenatal diabetes clinics in Norway, (Risa, 2011) found that the communication style of the midwives reduced opportunities for women to discuss any concerns they might have had. If the midwives spent more time talking, rather than offering opportunities to the women to openly discuss their concerns, there was less chance that the women would bring these issues up during consultations. The authors suggest that health care professionals should be more aware of and more open to, the emotional and psychological aspects of pregnancy for women with diabetes. Further, they suggested that to take advantage of the different competencies in a multidisciplinary diabetes team, the contribution of midwives to specialised antenatal care must be both recognised and defined (Risa, 2011)

The observations of this study indicate that health care professionals need to encourage and support women with type 1 diabetes to participate in the decisions about their diabetes management during pregnancy and ensure that the woman is recognised by herself and others, as an expert in her own diabetes management. Health care professionals must also have insights into their own behaviour, in order to enable the woman to express herself, and identify where they can best provide support. This is especially important for those caring for women at risk, given that they are reported to be more worried, anxious and vulnerable, compared to women in pregnancy without diabetes, and, therefore, have a greater need for support from others, particularly from health care professionals (Risa, 2011). These concepts

are supported by a small semi-structured interview study (Paiva et al., 2016) which identified five key themes: the fear of complications (both for the mother and the baby); the style of communication from health care professionals; the support of significant others; personal autonomy; and women's beliefs about pre-pregnancy counselling. The study concluded that women's experience of pre-pregnancy counselling is improved when health care professionals take a supportive and positive approach to communication, and acknowledge and address anxieties women may have about pregnancy preparation, as well as positively encouraging the desirable health related behaviours necessary for a healthy pregnancy and baby (Paiva et al., 2016). A second semi-structured interview study of 29 pregnant women (21 with Type 1, eight with Type 2, diabetes) at three UK specialist diabetes antenatal clinics (Murphy et al., 2010b) concluded that poor communication and previous difficulties with health care professionals were important barriers to pre-pregnancy counselling for vulnerable women. The authors recommended communication training for diabetes health professionals as a priority.

INTERNET BASED SUPPORT

The Internet has become an integral part of most people's everyday lives, affecting work and leisure time, and communication methods, and it has changed the way people seek and gather health information (Wong, Harrison, Britt, & Henderson, 2014). Use of the Internet for everyday communication is creating an abundance of social connections that have previously not been available, including websites, mobile Apps and social media (Wong et al., 2014). For women with type 1 diabetes this may offer connections to peers and health care professionals in preparing for and managing pregnancy, and provide multiple platforms for accessing information. It has been claimed that the provision of diabetes education and counselling via online methods might make it easier for the development of genuinely individualised and interdisciplinary diabetes management, and, ultimately, improved

pregnancy preparation (Griffiths et al., 2008). Indeed, people who are actively involved in their diabetes self-management and healthcare have been shown to be much more likely to manage their diabetes effectively (Shaw & Johnson, 2011).

The Internet can, therefore, become a way for people to manage their health and take control of this, which is particularly important for people with diabetes, where intensive self-management is critical (Shaw & Johnson, 2011). Previous research suggests that communication in relation to health, health status and health needs, is more effective when it connects with people on an emotional as well as a practical level, connects to their social life contexts, combines interpersonal communication and mass media, is tailored to them as individuals, and is interactive (Shaw & Johnson, 2011). There is very little prior work in relation to the potential for internet-based programmes and resource for women with type 1 diabetes in relation to pregnancy. The meta-synthesis in chapter five, provides evidence that the body of literature is small, despite its potential, and recommends further work.

SUMMARY

In summary, women with type 1 diabetes undergo a pregnancy journey that is similar in its time-phases, to other women. However, there is evidence that the issues and experiences at each point of the journey, differ to women without type 1 diabetes and require specific interventions and supports. There is compelling evidence that women's expertise in their own type 1 diabetes management should be acknowledged by health care professionals, and this is central to any discussions about pregnancy. It is recommended that communication about pregnancy be balanced, with insights into risks, coupled with a sense of optimism and strategies for a healthy pregnancy. Health care professionals working in diabetes and pregnancy might require additional training in communication styles, enabling opportunities for women to bring up issues and concerns. Shared-decision making and person-centred care is key. There is also evidence that timing is important, with repeated conversations about

pregnancy at perceived irrelevant times likely to have a negative impact on future engagement in pre-pregnancy counselling. Support is critical – from health care professionals, as well as peers, partner and family, where appropriate. Assessment and support of mental health and wellbeing should be included in preparation for pregnancy, and across the pregnancy journey. The issues of depression and diabetes specific distress need to be discriminated and more research is needed in this field. There are clear challenges and barriers to attendance at pre-pregnancy counselling, some of which have the potential to be addressed in a number of ways, and these will be discussed further in the studies following. The use of internet-based resources and programmes to provide education and support around pregnancy is important and is discussed in depth in the meta-synthesis in chapter 5.

ORGANISATION OF THESIS

This thesis comprises one published paper (chapter 3), and 2 chapters (chapters 4 and 5) presenting studies in manuscript format. There are 6 chapters. The first chapter presents a review of the literature related to diabetes and pregnancy. It highlights the high rate of adverse outcomes, low numbers of women with type 1 diabetes attending pre-pregnancy counselling, and the importance of positive, individualised, person-centred care, with attention to mental health and support systems. Chapter 2 presents the study rationale, research questions and methodological framework. Chapters 3, 4, and 5 present three empirical studies. Chapter 3 presents a published paper, using thematic analysis of online diabetes counselling records to develop a model of the journey of pregnancy for women with type 1 diabetes. Chapter 4 presents the development and pilot of a prototype Contemplating Pregnancy in Diabetes Communication Support Questionnaire, based on the literature and study one 1; and initial analysis of this prototype questionnaire, using cognitive interviews and scale reliability analysis. Chapter 5 presents a meta-synthesis of the qualitative literature, focusing on the recommendations for the use of internet-based programmes, social media,

and mobile Apps in pregnancy and type 1 diabetes. Lastly, chapter 6 presents the integrated findings from the 3 empirical studies and the contributions to knowledge gained from this research. Priorities for future research in this area are proposed.

CHAPTER 2: THEORY AND RESEARCH DESIGN

The purpose of this chapter is to provide an overview of the theory used in this work and the overall design of the research project. This thesis has been broadly informed by social cognitive theory, in particular, the Health Belief Model. Understanding and explaining constructs of optimism, hope and self-efficacy, in supporting women with type 1 diabetes during the pregnancy journey, were central. The work takes a mixed methods design, combining three sequential phases, with a predominately qualitative approach, which is explained further here.

THEORY

This research is broadly informed by Social Cognitive Theory (SCT). There are a number of models which fall within SCT. In particular, this research is based around concepts of the Health Belief Model (HBM), which is discussed in more detail later in this chapter. In general, SCT proposes that learning occurs within a social context and comprises both a dynamic and reciprocal interaction of the person, environment, and behaviour. These elements are continually interacting and affecting each other and the ways in which a person will behave and respond to the events and situations of their lives ("The Social Cognitive Theory," 2017). The emphasis on social influence, and external and internal social reinforcement are important to this work, because women with type 1 diabetes have been shown to benefit from positive social support and a sense of optimism when planning and undertaking a pregnancy (Anderberg, Berntorp, & Crang-Svalenius, 2009; Berg, 2005; Berg & Honkasalo, 2000; Berg & Sparud-Lundin, 2009; Sparud-Lundin & Berg, 2011).

SCT considers how people develop and maintain behaviours within the social environment in which they live ("The Social Cognitive Theory," 2017). SCT also considers a person's past experiences and how these might affect the ways they choose to take an action currently, or in the future - the experiences a person has had in the past, are likely to influence and

reinforce future behaviours. For women with type 1 diabetes, the social environment has been shown as influential in relation to their actions to stay healthy, manage their type 1 diabetes, and prepare for pregnancy (Adolfsson et al., 2014; Berg, 2005; Berg et al., 2013). As discussed in chapter 1, past and current interactions with health care professionals, family and peers, contribute positively to their experiences of pregnancy and motherhood and also contribute to whether they will seek pre-pregnancy counselling (Berg, 2005; Berg & Sparud-Lundin, 2009; Griffiths et al., 2008; King & Wellard, 2009; Lavender et al., 2010; Murphy et al., 2010b). Despite some of the tasks of diabetes management during pregnancy for women with type 1 diabetes being more intense than usual, many of these are essentially the same behaviours required during all of their lives. Therefore, maintenance of such behaviours, and what supports those behaviours usually, and during pregnancy, is particularly important. This means that women with type 1 diabetes require knowledge about what to expect during pregnancy, the changes that might occur to their diabetes, how to address these changes, and what to do when they have concerns. Along with this they require positive support from family, peers and health care professionals (Abell et al., 2016; Adolfsson et al., 2014; Berg, 2005; Berg et al., 2013; Berg & Sparud-Lundin, 2009).

SCT aims to explain how people self-regulate their behaviour through control and reinforcement, so that they can reach their goals relating to their health, and sustain these actions over the long term ("Health Communication | Social Cognitive Theory," 2017). SCT includes cognitive, emotional, and behavioural aspects, in understanding behaviour change (Bandura, 1977). Within SCT, a person's environment, support systems and their own behaviours, are seen to constantly influence each other. The environment a person lives within provides models for behaviour, and observational learning occurs through observing another person and the reinforcements that they receive (Bandura, 1997). This includes their physical, social, community and political, environments.

For women with type 1 diabetes the social environment may include their partner, family, peers, and relationships with health care professionals. Physical environment may include elements such as the availability of tools and technology to manage diabetes, access to healthy food and exercise options, and access to pre-pregnancy counselling itself. Peer support and connections are central. The political environment and health policies also play an important role, supporting increased funding to programmes, pregnancy and diabetes clinics, management technologies and the development of tools such as pregnancy apps and websites (Adolfsson et al., 2014; Anderberg et al., 2009; Berg et al., 2018; Edwards et al., 2016).

It is of note that as well as the HBM, the Transtheoretical Model of Health Behaviour Change (Prochaska & Velicer, 1997) was considered, but was not thought to be analogous with this work. The Transtheoretical Model proposes that health behaviour change involves progression through six stages of change: precontemplation, contemplation, preparation, action, maintenance, and termination. Ten processes of change have been identified for producing progress, along with decisional balance, self-efficacy, and temptations (Prochaska & Velicer, 1997). Whilst some elements of this model might be relevant, such as self-efficacy, the journey of pregnancy discussed in this thesis is related to time-phases, rather than a linear process of behaviour change. 'Contemplation' as it relates to this work, is in regard to women's consideration of potentially becoming pregnant, rather than contemplation of particular behaviour changes. Based on the literature and the findings of study one, there is no definite linear process of behaviour change experienced by every woman with type 1 diabetes who contemplates pregnancy. They will come to pregnancy Contemplation with a variety of past experiences in relation to their own diabetes, relationships with health care professionals, and their knowledge about pregnancy planning. These will all affect their desire and ability to maintain the behaviours needed for pregnancy. The Transtheoretical

Model suggests that only a minority (usually less than 20%) of a population 'at risk', is prepared to take action at any given time (Prochaska & Velicer, 1997). However, in this case, it is clear that many women are likely to have already been undertaking specific health-related behaviours to manage their type 1 diabetes, over a period of years (Komiti et al., 2013). Once aware that pre-pregnancy counselling exists, and that this is important, many women with type 1 diabetes are apparently highly motivated to participate in this and undertake the behaviours needed for a healthy pregnancy (Morrison et al., 2018).

The Health Belief Model ("Health Communication | Health Belief Model," 2017), however, fits well with the constructs of this thesis in relation to its purpose as well as the specific ways in which the constructs of the theory, fit with the topic. This is a specific form of Social Cognitive Model which aims to explain and predict health behaviours. This was therefore used as the theoretical framework for this thesis.

The HBM is based on the belief that a person will take a health-related action if that person:

1. feels that a negative health condition can be avoided;
2. has a positive expectation that by taking a recommended action, he/she will avoid a negative health condition; and
3. believes that he/she can successfully take a recommended health action ("Health Communication | Health Belief Model," 2017).

When developed in the 1950s by social psychologists Hochbaum, Rosenstock and Kegels working in the U.S. Public Health Services, the HBM originally incorporated four constructs:

1. perceived *susceptibility*
2. perceived *severity*
3. perceived *benefits*
4. perceived *barriers.*

These concepts were suggested as explaining why someone would experience ‘readiness to act’ in relation to their health. Cues to action, the aspects of a person’s world that might activate that readiness, and encourage the healthy behaviours required, are very important (Jones et al., 2015). The evidence presented in chapter 1, shows that this is important for women with type 1 diabetes in attending pre-pregnancy counselling and preparing for pregnancy. Regular cues to action around pre-pregnancy planning, delivered at times that are relevant to her, in a positive manner, can increase women’s propensity to seek support when considering a baby.

In 1988 Rosenstock and others added the concept of self-efficacy, which relates to a person’s confidence in their ability to perform a needed action successfully. If they believe they have the capacity to make the recommended changes to their behaviour, they are more likely to act. This concept was added to support the HBM to better fit the challenges of changing habitual unhealthy behaviours, such as being sedentary, smoking, or overeating, which require long term maintenance. ("Health Communication | Health Belief Model," 2017).

This aspect of the HBM fits well in relation to type 1 diabetes and pregnancy, where there is a need for tight management of blood glucose levels prior to pregnancy and throughout pregnancy. It has been shown that women need to understand the risks of pregnancy with type 1 diabetes, feel that there are things they can do to reduce these risks, and feel that they are capable of taking these steps and maintaining them over potentially, an extended period of time. As discussed in the literature review, during pregnancy, the desirable health-related behaviours for women with type 1 diabetes must be carried out in even more challenging circumstances than usual. It can include potentially long periods of preparation prior to pregnancy. Further, a woman with type 1 diabetes’ self-efficacy, sense of optimism, and her preparedness for pregnancy, may all vary over time. Women with type 1 diabetes have been

reported to respond to messages that the adverse outcomes of pregnancy can be avoided, and which encourage them to develop positive expectations that by taking recommended actions, they will be much more likely to have a healthy pregnancy. The interactions between women and health care professionals need to support the belief that they can successfully take those recommended health actions (Linden, Berg, Adolfsson, & Sparud-Lundin, 2018; Linden et al., 2016; Murphy et al., 2010b; Rasmussen, 2012).

Pregnancy for women with type 1 diabetes, therefore, requires both self-efficacy and optimism. Optimism supports the likelihood that a person will take action towards healthy behaviours (Sweeny et al., 2006). Optimism is however a fluid concept, that can change depending on a variety of factors and preparedness for all potential outcomes, affects these fluctuations in optimism (Sweeny et al., 2006). Optimism might encourage women with type 1 diabetes to develop a positive mindset that they can do what is needed, irrespective of the challenges, and succeed with confidence. On the other hand, pessimism can also be useful, as it can facilitate preparedness for possible undesirable outcomes, and encourage a person to take action to prevent or remedy these (Sweeny et al., 2006). Therefore, in some cases, a slight shift away from optimism can establish that the person has realised things may not turn out as they hoped, but that they are motivated to do something about that. They believe they can affect the outcomes to some degree. However, people might shift too far away from optimism, towards pessimism, when they feel the outcomes are not at all within their control (Sweeny et al., 2006).

Optimism about positive pregnancy outcomes, might therefore relate to how confident a woman with type 1 diabetes feels about her ability to manage her diabetes during pregnancy. This involves developing self-efficacy, self-confidence and self-esteem. People with low self-esteem can become less certain of their abilities, and consider more of the things that may go wrong, than someone with higher self-esteem (Sweeny et al., 2006). Indeed, a very

pessimistic outlook can lead to negative affect and anxiety, which can become crippling in relation to taking positive action (Sweeny et al., 2006). It can be postulated that this might reflect the reasons behind why some women with type 1 diabetes turn away from health care services when overly negative messages are given to them about pregnancy, without any positive messages and the belief that they can overcome the potential risks.

As discussed in the previous chapter, women with type 1 diabetes may already have higher levels of anxiety about pregnancy, than women without diabetes. They may experience diabetes distress and reduced wellbeing across the pregnancy journey (Do et al., 2017; Egan et al., 2017b; Griffiths et al., 2008; Langer & Langer, 1998). Self-efficacy is important in feeling confident that they can overcome the potential difficulties, carry out the extensive tasks needed, and as a result, be more likely to have a healthy pregnancy and baby. In order to succeed, they must maintain healthy self-esteem and positive wellbeing during this process (Abell et al., 2016; Dalfra et al., 2012; Edwards et al., 2016; Egan et al., 2017c; Fisher et al., 2012; Linden et al., 2016).

One of the recurring themes in this thesis, is that research consistently shows prior negative communication by health care professionals in relation to pregnancy, can prevent women with type 1 diabetes from attending pre-pregnancy counselling (Egan et al., 2016; Egan, 2015). This negative communication is likely to encourage low self-esteem and pessimism about pregnancy. Health care professionals have the opportunity to support women with type 1 diabetes to preparedness for pregnancy and increased optimism about their ability to undertake a positive pregnancy journey. This must be carried out in a balanced, person-centred manner. There needs to be an awareness of the risks and a sharing of information about how to avoid these, coupled with self-belief. Ultimately it is suggested that a balance between optimism and pessimism, best supports preparedness (Sweeny et al., 2006). People require enough optimism to take advantage of the many benefits of a positive outlook, but be

able to balance this with enough of a shift away from optimism, to increase their motivation towards preventive action, and avoid being unprepared for what may come (Sweeny et al., 2006).

A person-centred approach to health care can increase self-efficacy, therefore improving people's health-related quality of life. Higher levels of self-efficacy are reported in this approach (Pirhonen, Olofsson, Fors, Ekman, & Bolin, 2017). Person-centred care refers to a type of care where the care provider focuses on the needs and resources of the person they are helping. It can be defined as 'co-creation of care' between the person, their family, informal care takers, and health professionals (Pirhonen et al., 2017). In relation to support systems, as shown in chapter 1, the health care professional relationship is influential when it comes to managing pregnancy with type 1 diabetes. A respectful partnership supports women to feel more positive about what lies ahead.

In relation to the social and political environment, a meta synthesis (Forde, Patelarou, & Forbes, 2016) found that many health care professionals identified limitations in the health care system as having a significant impact on the delivery of pre-pregnancy counselling. A particular challenge identified was the delivery of care across different services and professions. The relationship between primary care and specialist diabetes care, was seen as problematic by some. They described a lack of shared understanding and agreement about how to best provide pre-pregnancy counselling and care, and who should do this.

In contrast, other health care professionals have emphasised that the fundamental issue is not about *who* provided this care, but that it was consistent. For many, particularly those in primary care, rationing in the organisation and meeting clinical outcome targets, meant that pre-pregnancy counselling was not a priority. Suggestions were that health care professionals need to be supported to develop consultation skills that elicit women's pregnancy intentions

and allow them to talk about any of their concerns, needs and anxieties, as well as developing a positive and productive relationship for future pregnancy planning.

METHODOLOGY

This research project uses a mixed methods approach, with a sequential explanatory design, consisting of three phases (Phillip Bowen, Rose, & Pilkington, 2017). The qualitative phase was primary, meaning more weight was placed on the qualitative phase and methods, and the qualitative data obtained in all phases of the work. When undertaking mixed methods research, it is important to ask whether this way of working will add more value than a single method (Phillip Bowen et al., 2017). In this project, that was considered to be the case, given the predominately qualitative focus, with the addition of a more quantitative phase considered to add depth to the work.

Following phase 1, my supervision team suggested I consider the development and testing of a Questionnaire for phase 2, which might address some of the research problems appropriately, as well as providing a deeper understanding than the thematic analysis of study 1 alone. The qualitative data analysed in the thematic analysis, provided some understanding about the experiences of pregnancy for women with type 1 diabetes, the phases of the journey, and identified the important issues for such a Questionnaire.

After an evidence-based process of Questionnaire development, a pilot study of the Questionnaire (presented in chapter 4), used basic psychometric testing to ascertain face and content validity. The qualitative data gathered from the cognitive interviews in this phase, however, had just as much importance to the final conclusions of the project. In the final phase 3, given the findings of phase 1 and 2 in relation to the importance of online resources, a qualitative meta-synthesis was undertaken, to ascertain the current research in relation to internet-based resources and programmes and where there might be gaps in knowledge, making recommendations for further work.

Phase 1

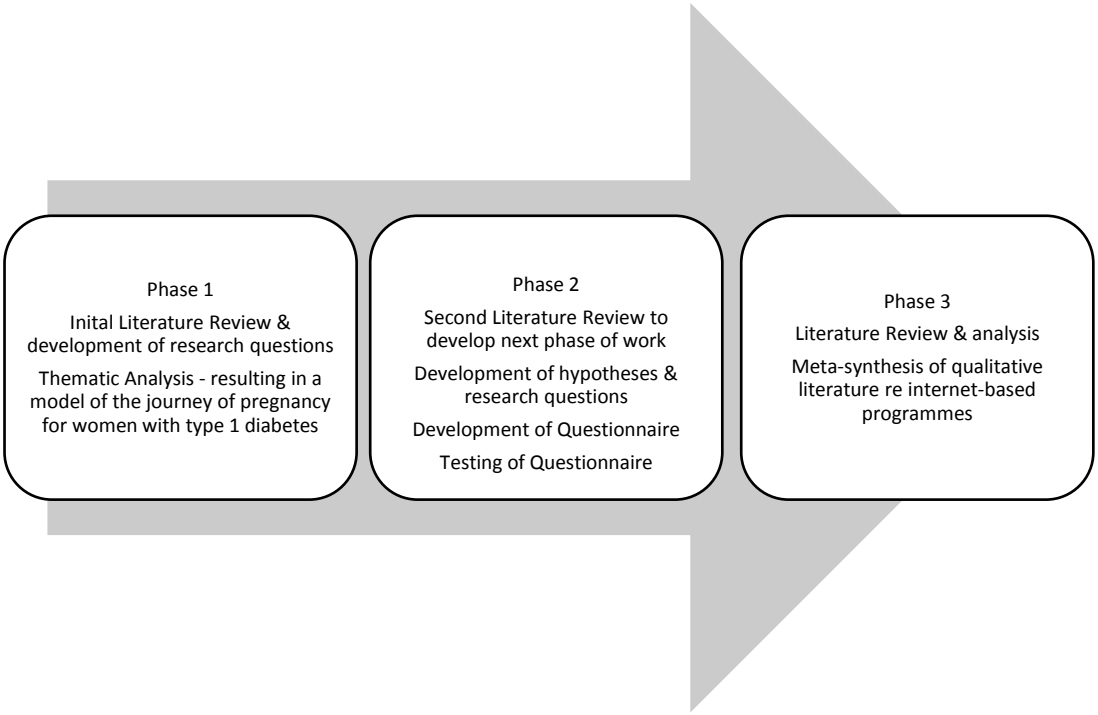
Phase 1 included an initial literature review, followed by development of the research questions and the focus on understanding the experiences of pregnancy for women with type 1 diabetes. In particular I was interested in mental health and wellbeing, as well as peer support and internet-based resources. I then carried out a Thematic Analysis of online diabetes counselling records, which resulted in a model of the journey of pregnancy for women with type 1 diabetes.

Phase 2

Phase 2 firstly consisted of an in-depth literature review and analysis of the original data from the thematic analysis in phase 1. This informed the development of the Questionnaire, which took a 5-phase development process, followed by preliminary testing for reliability. The data were gathered and analysed using basic psychometric testing.

Phase 3

In the final phase 3 study, as internet-based programmes and resources formed the basis of the initial study, a meta-synthesis of the qualitative evidence supporting internet-based programmes, social media, and mobile Apps, was undertaken. This was further informed by the evidence in the literature that better communication and wider awareness of the importance of pre-pregnancy counselling in type 1 diabetes is needed. Finally, internet-based resources for pregnancy and type 1 diabetes were seen as a gap needing further work in the literature.



When all of these methods and data are combined, they provide a more rounded piece of work. Mixed methods research has been used since the 1950's but began formally in the late 1980's, and is increasingly used by a growing number of researchers (McKim, 2015). Studies incorporating a mixed methods approach can obtain a more thorough and deeper understanding of the phenomenon being considered (McKim, 2015). The integration aspect of mixed methods research can offer more confidence in the results and the conclusions of the study, as well as providing researchers with new ideas for future research and hypotheses (McKim, 2015). Mixed methodology may or may not include both quantitative and qualitative methods, but can also simply describe quantitative and/or qualitative data, combined within a single study, complementing each other by integrating their strengths (Phillip Bowen et al., 2017). This is the case with this thesis, where I combine a well-established qualitative method of thematic analysis, with an evidence-based questionnaire development process, qualitative and basic quantitative approaches to testing the Questionnaire, and finally, a qualitative meta-synthesis.

Qualitative research considers the concepts being studied from the perspective of the people involved in the research project. There are two underlying principles: 1) that behaviour is influenced by the physical, sociocultural, and psychological environment; and 2) that there is more underlying human behaviour than what you can actually observe in your research (Krefting, 1991). Subjective meanings and the perceptions of the people included in the study, are important aspects of qualitative research. It is the researcher's responsibility to uncover these. In some qualitative approaches, the major purpose is simply to generate hypotheses for further investigation, rather than to test them (Krefting, 1991). A qualitative study is seen as credible when a person involved in the study can recognise their own words within the results, or when other researchers or readers for example, can recognise the experiences being presented after having only read about them (Krefting, 1991).

Quantitative methods usually determine whether threats to internal validity have been managed. In development of a questionnaire, such a research instrument is considered valid when there can be confidence that it in fact measures what was intended (Sandelowski, 1986). This includes measuring what is being studied as it is defined within the study (content validity); whether it compares well with any other tests measuring the same phenomenon (criterion-related validity); and that the results are congruent with the theory around the construct being studied (construct validity) (Sandelowski, 1986). In this thesis there were limitations as to how much of this process could be carried out, due to the low number of respondents to the pilot survey. This is discussed in chapter 4. However, basic psychometric testing and cognitive interviews still provided some analysis of face and content validity and helped prepare the Questionnaire for further work. Construct validity was assured through the process of framework development based on the literature and study one.

Philosophical ideas, or the basic set of beliefs that guide your own actions, influence the practice of research and should also be identified in any research project (Creswell, 2014).

When you can identify and understand the philosophical ideas behind your work, you obtain deeper understanding about why a particular methodology was selected (Creswell, 2014). These philosophical standpoints, or ways of seeing the world, will be related to the researcher's discipline and orientations, their advisors or supervisors' beliefs, and their past research experiences - and, the researcher's own beliefs will often result in the decision to choose either a qualitative, quantitative, or mixed methods approach to their research (Creswell, 2014). In my case, my background as a social worker, predominately qualitative approach to prior research, and personal values, affected my decision to focus mostly on qualitative approaches. My supervisors' disciplines and prior research, guided me to the inclusion of some quantitative methodology in the work. Thus, the final result is a mixed-method research project.

There are a number of accepted philosophical viewpoints that impact research methodology. Firstly, in a post-positivist approach, the assumptions relate mostly to quantitative research (Creswell, 2014). A researcher using this viewpoint believes that causes determine effects, or outcomes. Therefore, the research problems studied by post-positivists are based around identifying and assessing the causes which influence outcomes, such as those discovered during experiments. This approach is reductionistic, because the aim is to reduce the ideas into small, discrete sets of data that can be tested (Creswell, 2014).

Social constructivists, on the other hand, believe people want to understand the world they live within. People are therefore seen as developing subjective meanings about the experiences they have, and place meanings on certain objects or things, understanding the world from their own perspective. This approach leads to the researcher looking at the complexity of views that exist in the world. Generally, researchers using a social constructivist approach will value each individual's experiences and understandings, rather than trying to contain meanings to a handful of pre-conceived categories or ideas, or by

reducing concepts into small, discrete sets of information to be tested (Creswell, 2014). The goal of this type of approach is to, as much as possible, develop understanding about the constructs being studied from the participants' views about the world, and the subject matter being studied. This is often relevant to a qualitative approach (Creswell, 2014) and underpins the thematic analysis, cognitive interviews, and meta-synthesis components of this work.

A transformative worldview is based on the belief that the way the research is carried out should be connected to the political and social environment, and that social oppression should be confronted at all levels (Creswell, 2014). In such an approach, the researcher will have a goal for social change and the aim to affect the participants lives, the institutions in which they work or live, and, the researcher's life. In addition, such research will work to address specific social issues of the day (Creswell, 2014). As part of this research project, there is certainly an interest in offering information to the field that might lead to work aimed at overcoming barriers in the health system and at the policy level, to make pre-pregnancy counselling more widely available, and to increase resources in the health care system for pregnancy and type 1 diabetes. Finally, Pragmatism is not committed to any particular or exclusive philosophy and reality (Creswell, 2014). This approach applies to mixed methods research because researchers can select the methods, techniques, and procedures of research, that best meet their needs and purposes at the time. Mixed methods researchers can take a range of approaches for collecting and analysing data from qualitative and quantitative data, rather than selecting just one. There is no set balance between the two approaches – but there tends to be a leaning towards one, or the other. The combination of both adds weight to the work (Payton, 1979).

CONTEXTUAL STATEMENT STUDY 1

The following chapter documents the first study of this work, which develops a model of the journey of pregnancy for women with type 1 diabetes. This contributes to the growing body of qualitative knowledge in relation to pregnancy for women with type 1 diabetes, in particular, providing unique insight into their experiences and support needs during each time phase of the pregnancy journey. This informs the later phases of the study and results in the decision to focus on the Contemplation phase of pregnancy in study two. It also informs the decision to evaluate the qualitative literature looking at internet-based resources in study three.

CHAPTER 3: A QUALITATIVE MODEL OF THE PREGNANCY JOURNEY FOR WOMEN WITH TYPE 1 DIABETES

PREAMBLE AND INTRODUCTION

This chapter describes the first study, a thematic analysis of written counselling records submitted to the Diabetes Counselling Online services (DCO), between 2002 and 2012. As this is a study of retrospective data, in written word, it is appropriate to use Thematic Analysis. Thematic Analysis is a method for identifying, analysing and reporting patterns or themes within data. It offers an accessible and theoretically flexible approach in analysing qualitative data and can potentially provide a rich and detailed, yet complex, account (Braun & Clarke, 2006).

This study was carried out with an inductive analysis, to explore the subjective experiences of the women. As there was access to the narratives as written, this fits well with such an approach. Each story was seen as unique, whilst drawing on certain observations found to be present within, and similar across, each record of counselling. The aims of this study were to understand the experience of pregnancy and early motherhood for women with type 1 diabetes, to gather deeper understanding of their experiences, in particular in relation to wellbeing, diabetes distress and depression; fill gaps from the literature, and examine whether this study supports ideas discussed in prior research and/or introduces new ones; as well as refining the focus for studies two and three.

DCO www.diabetescounselling.com.au was a free internet-based counselling service for people with diabetes and their families, which I founded in 2001. It operated until mid-2016. The service delivered online counselling and diabetes education via email, group peer support, discussion forums and chat sessions, sharing of diabetes stories, email-buddies programme (prior to social media) and Facebook groups (once this platform became available). All counsellors were qualified in diabetes education and/or mental health, and had

personal experience of diabetes, giving a unique blend between peer and professional support and insight. Archived records from the inception of the organisation were available to me for this study.

Delivery of internet-based counselling since 2002 provided vast amounts of data, about both the issues presented to the service, and the help seeking behaviour of people with diabetes on the Internet. Over this time there were requests for support from women with issues relating to pregnancy and motherhood. This offers a unique window from which to view their experiences at the time they sought help. In particular it gives opportunity to consider the pregnancy contemplation and planning phases, which are can be difficult to capture, because women might be thinking about pregnancy at some time in the future, but not necessarily sharing this with their usual health care team. Study one was pivotal in the decision to focus on pre-pregnancy planning and the phase of Contemplation in study two; and in reviewing internet-based programmes and resources in study three.

This study was published as a journal article, the content of which is presented here in full, following the Statement of Authorship. A number of questions were developed prior to undertaking the analysis, based on the initial literature review at the outset of the work:

- What are the issues women with type 1 diabetes bring to the DCO website around pregnancy and early motherhood?
- What prior experiences do they have with health care professionals in relation to pregnancy information and support? How useful has this been and where are the gaps in relation to pregnancy information and support?
- How have family, friends and peers been involved in women's prior experiences of pregnancy information seeking, and/or during pregnancy?
- Are women with type 1 diabetes attending pre-pregnancy counselling, and at what point? Are they seeking information from other sources and if so, what are they?

- Is diabetes specific distress present during the pregnancy journey, and if so, what is the nature of this at various time points and how is this identified?
- Do women experience depression at any stage of the pregnancy journey and how is this identified?

Following the analysis, I asked - do the themes discovered support current research, expand or differ on this? What new ideas are emerging from the study? What other aspects stand out in the themes? What questions am I left with for the next studies in this thesis?

STATEMENT OF AUTHORSHIP

Title of Paper: The Pregnancy Journey for Women with Type 1 Diabetes: A Qualitative Model from Contemplation to Motherhood.

Publication Status: Published ***Publication Details:*** Edwards, H, Speight, J, Bridgman, H, Skinner TC. (2016). The Pregnancy Journey for Women with type 1 diabetes: A Qualitative Model from Contemplation to Motherhood. Practical Diabetes; Volume 33, Issue 6; DOI: 10.1002/pdi.2036

Name of Principal Author: Helen Edwards (Candidate)

Contribution to the paper: Developed study focus, carried out literature review, designed and carried out thematic analysis, identified themes and phases, coded all data, revised analysis based on feedback, developed the model of the journey of pregnancy, presented results at international and national conferences, drafted paper for publication and responded to all feedback for final paper submission.

Overall Percentage: 70%

Certification: This paper reports on original analysis during my higher degree by research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.

SIGNATURE: **DATE:** 15/4/19

3.1. ***Co-Author Contributors:*** By signing the Statement of Authorship each Author certifies that:

1) The Candidates stated contribution to the publication is accurate (as detailed above)

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PUBLISHED PAPER

The Pregnancy Journey for Women with Type 1 Diabetes: A Qualitative Model from Contemplation to Motherhood

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ABSTRACT

Purpose: The purpose of this study is to describe and develop a model of the pregnancy journey for women with type 1 diabetes (T1D).

Methods: Thematic analysis of written interactions (N=200; N=2,060 text excerpts) with an online counselling support service from 93 women with T1D.

Results: Seven possible discrete phases in the pregnancy journey were revealed: Contemplation, Pregnancy Planning, Conception, Pregnancy, Delivery/Birth, and Motherhood (or Pregnancy Loss). Eight common themes were identified, varying in importance across phases. Diabetes-specific distress was most evident during Contemplation and Motherhood. During pregnancy, 'social identity and peer support' were paramount. Negative emotions in Pregnancy, whilst connected to diabetes, also centred on the unborn

baby. In Motherhood, diabetes-specific distress and depressed mood increased. Medicalisation was expected and offered reassurance during Pregnancy; however, some women still worried, with peer support offering the most reassurance.

CONCLUSIONS: Women with T1D potentially experience seven distinct phases of the pregnancy journey, with eight themes varying in significance across phases. Contemplation begins well before Planning or Conception, and women may seek support from non-mainstream sources. 'Mental health and emotional well-being' vary qualitatively and quantitatively across phases (focusing on pregnancy-related distress, diabetes-specific distress and general maternal well-being), indicating a need for targeted assessment and support across the pregnancy journey.

Word count 200 (max 250)

Keywords Type 1 diabetes, Pregnancy, Pre-Pregnancy, Motherhood, Qualitative study

Key Points

- This study reports on perspectives of women with type 1 diabetes pre-pregnancy.
- This study reports on the accounts of women with type 1 diabetes accessing support outside traditional health services to understand their pregnancy journey, concerns, experiences and support needs.
- This model can potentially assist healthcare professionals anticipate the needs of pregnant women with type 1 diabetes to support their emotional wellbeing, as well as their blood glucose regulation.

Type 1 diabetes is one of the most common pre-existing medical conditions complicating pregnancy, with potentially devastating outcomes for both mother and child if the condition is not managed well. Such complications include significantly elevated risks of obstetric and foetal complications including preeclampsia, prematurity, still birth, malformations, the foetus being large for gestational age and neonatal morbidity [1].

Despite advances in knowledge and care, management of pregnancy for women who have type 1 diabetes remains challenging. The St. Vincent's Declaration of 1989 set as a five-year target, the reduction of adverse pregnancy outcomes in women with type 1 diabetes, to a level equal to that of women without diabetes [2]. More than two decades later, Colstrup and colleagues, however, found the risk of adverse pregnancy outcomes in women with type 1 diabetes to be between two to five times that of the general population, concluding that the goals of the St. Vincent's Declaration had not been achieved [3].

Whilst pre-pregnancy counselling greatly improves these outcomes [4] many women do not engage in this process with their healthcare team [5]. In order to improve outcomes, we need to understand why women are not attending pre-pregnancy counselling and what their needs are before, during and post the pregnancy journey. Studies exploring the views of pregnant women who did not attend pre-pregnancy care have concluded that three issues need addressing: 1) integrated diabetes and reproductive health/contraceptive advice, 2) increased awareness of the potentially short interval between stopping contraception and conception, and 3) more intensive support between pregnancies, particularly for women with previous adverse pregnancy outcomes [5]. Others have emphasised that pre-pregnancy care needs to make better use of social media and that health professionals could facilitate peer support to encourage uptake of pre-pregnancy services [6]. However, as Rasmussen and colleagues note in their review [6], none of the studies undertaken to date, have collected data before individuals were pregnant. Rather they have relied on retrospective accounts of women later on, with the inherent biases that may incur.

In addition to the lack of engagement with appropriate pre-pregnancy care, both diabetes-specific distress and general distress during pregnancy have been implicated as possible contributors to adverse pregnancy outcomes. Thus, in a small number of studies, it has been

suggested that women with type 1 diabetes are more vulnerable to experiencing psychological distress during pregnancy than women without diabetes [8-10].

Kozhimannil and colleagues [9] reported that women with type 1 diabetes were at twice the risk of perinatal depression, whilst Katon and colleagues reported 54% higher odds of any antenatal depression in women with pre-existing diabetes compared to those without [10]. Two reviews of the qualitative literature on diabetes in pregnancy also support these findings [7,11]. Studies documenting the demanding and stressful nature of diabetes during pregnancy tend to focus on blood glucose control outcomes, rather than the experiences of the mother and her need for support during pregnancy and motherhood. [12-14]. Berg and colleagues have also explored the experience of early motherhood and breast feeding for women with type 1 diabetes (15,16), although data were collected only after childbirth.

As noted in recent reviews [7,11,17, 18], there are generally very limited data on the reported emotional experience of pregnancy for women with pre-existing diabetes especially from the woman's perspective. Further, to our knowledge, no longitudinal studies have reported on data across the entire journey, from pre-pregnancy onwards. Given there are likely to be different challenges experienced by women at different stages of the journey, from conception to delivery (or miscarriage), we sought to describe the journey experienced by women with type 1 diabetes, and to develop a preliminary model of this journey, to help inform future research and service provision.

REASEARCH DESIGN AND METHODOLOGY

As a first step in understanding the experience of women with type 1 diabetes surrounding pregnancy the electronic 'conversations' held between the 'Diabetes Counselling Online' (DCO) service and women with diabetes were reviewed. DCO is a not-for-profit organisation, providing a free internet-based counselling service, and psychosocial / informational support via social media predominantly to people with diabetes. DCO provides

support largely to people whose needs have not been met by traditional diabetes care services, or who are unable to access traditional care services. This unique service is predominantly used by Australians who comprise approximately 60% of users, followed by visitors from the USA and UK.

All email counselling and 'buddy' requests (stored verbatim as hard copies) received by DCO between 2002 and 2012 were reviewed. Records were retained for analysis wherever pregnancy, parenting, motherhood (up to two years post-natal) or issues relating to these were mentioned by women who self-reported having type 1 diabetes. Further data were taken from discussions on the DCO pregnancy forum, 'Your Stories' and the 'Your Stories' Facebook group.

As DCO provides a standing website disclaimer about the potential use of data for research purposes, appropriate institutional ethics approval was granted to access anonymised, archived records of counselling and email buddy conversations. As the 'Pregnancy and Parenting' Facebook page supported by DCO commenced in 2011, individual consent was sought from the women accessing this page to participate in the study. Of these 23 women, eight (35%) consented to the use of their postings anonymously for the study. Data was collected from this page from December 2011 to August 2012.

In total there was data available from 93 women with data sourced from email buddies (n=9), email counselling (n=48), 'Your Stories' (n=9), the DCO pregnancy forum (n=19) and the 'Pregnancy and Parenting' Facebook page (n=8). Number of interactions per woman ranged from 1 to 44. As this was a naturalistic study, country of origin data was available only for women who accessed the online counselling, email buddy services or Facebook page. All of these women were Australian.

De-identified transcripts were provided by DCO to the research team and entered into NVivo for analysis. One investigator (HE), undertook the initial analysis and coded

transcripts thematically using a framework approach, which included reading and re-reading data numerous times, to ensure familiarisation. Each piece of written content was broken down into distinct blocks of text, with each block representing a single distinct issue as determined by the principal coder. An initial coding frame was developed, which was used to develop over-arching themes. Themes were reviewed and refined continually by the research team, until they were considered to best represent the data. The research team comprised three psychologists and a counsellor; of male and female genders, with and without children. The coding framework was reviewed and discussed several times by the research team. Once consensus was reached, all data were coded in NVivo and descriptive analysis undertaken.

RESULTS

A total of 200 interactions by 93 women, recorded over a period of 10 years, were extracted generating 2,060 text excerpts for coding and analysis. Percentages are shown to demonstrate frequency of content among the text excerpts. Analysis revealed seven distinct phases of the pregnancy journey: Contemplation (18% of text excerpts); Pre-pregnancy Planning (4%); Conception (10%); Pregnancy (28%); Loss (3%); Delivery and Birth (10%); and Motherhood (27%). These phases were used to provide temporal structure for the data and to enhance understanding of women's experiences over time.

Analysis revealed eight major themes (presented alphabetically below) across the seven phases of the pregnancy journey, which encapsulated the data and were identified as common across participants. See Table 1 for exemplar quotes.

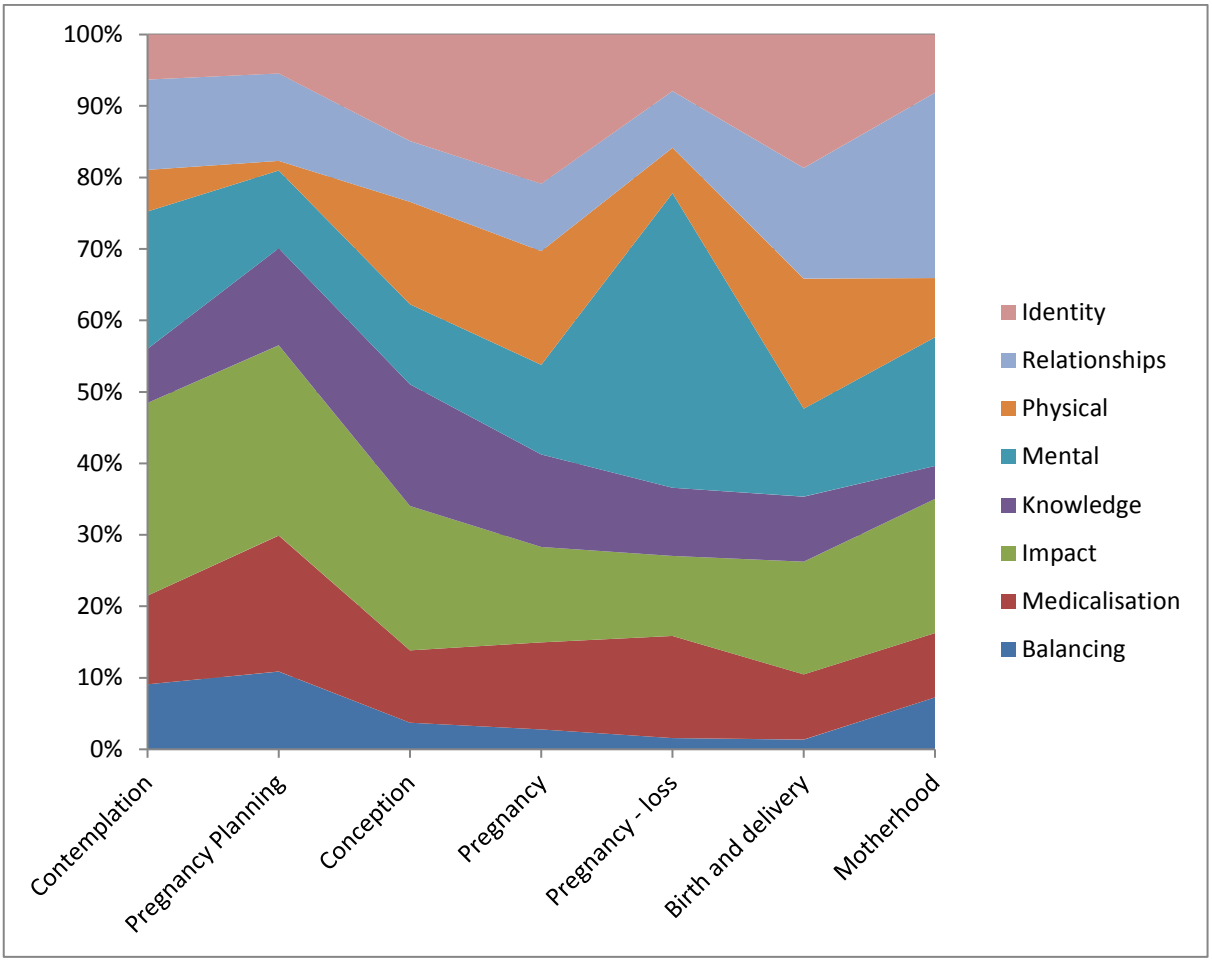


Figure 1: Distribution of Theme Codes by Phase

Balance and Juggling (5% of text excerpts)**:** Participants wrote about a struggle to balance diabetes self-management against other aspects of life, such as work, family and social life. The priority afforded to diabetes self-management varied substantially across the journey. Initially, this became all-consuming during 'planning' and 'pregnancy' but, in the postnatal phase, this became the least of the new mothers' priorities.

Healthcare Professionals (HCPs) and Medicalisation (11% of text excerpts)**:** Women were accepting of (and expected) medicalisation during 'pregnancy'. They found, in particular, medical checks on the unborn baby's gestation and health reassuring. At the time of 'delivery and birth', they also were accepting of this but were distressed by their lack of personal control over the birth. Negative experiences across the journey included not wanting to tell health professionals they were pregnant or to ask questions of HCPs due to past

experiences or unrealistic expectations. Some women felt they understood their diabetes better than anybody else, and that this was not acknowledged by their HCPs. Positive experiences included receiving positive and affirming feedback from HCPs.

Impact of Diabetes on Experience of Pregnancy (19% of text excerpts)**:** How well women were managing their diabetes prior to becoming pregnant impacted upon the way they felt during 'pregnancy'. Those who presented in 'contemplation' wanted to work on their sense of personal control in preparation for a possible pregnancy. During 'pregnancy', the unpredictability of diabetes was a major concern. Hypoglycaemia was mentioned in a number of phases and was most evident in the interactions during 'pregnancy'. In 'motherhood', women expressed concerns about hypoglycaemia and the ability to care for their child.

Knowledge Seeking and Application (8% of text excerpts)**:** Use of existing knowledge and seeking of new knowledge was highest during 'pregnancy', with women wanting to understand as much as possible about what was happening by seeking new information and to use their existing knowledge of their diabetes and their body in managing their pregnancy.

Mental Health and Emotional Wellbeing (16% of text excerpts): Diabetes-specific distress, as usually defined [18], was coded most frequently during 'contemplation', when women were dealing with their health and diabetes history, followed closely by 'motherhood', when intense balance and juggling occurred. During 'pregnancy', the diabetes-specific distress expressed by women was qualitatively different, focused on a heightened anxiety about the baby. General negative emotions such as stress and worry about the future, added to the mental health impacts in 'motherhood'. At all points during the journey, it was evident that women were reaching out for acknowledgement, reassurance and normalisation of their experiences. Depressed mood peaked in 'motherhood', with some women reflecting on experiences of depression that had continued or reappeared and others experiencing

depressed mood for the first time. Some felt their partner was unable to understand what they were experiencing. The combination of changes to diabetes management, balance and juggling, learning to be a mother, lack of understanding and fatigue, fed into depressed mood.

Physical Health: Mother and Child (11% of text excerpts)**:** Concerns relating to the general physical health of the woman and her baby and in particular, the health of the baby from 'conception' onwards, peaked during 'pregnancy' when the development of the unborn baby was all consuming.

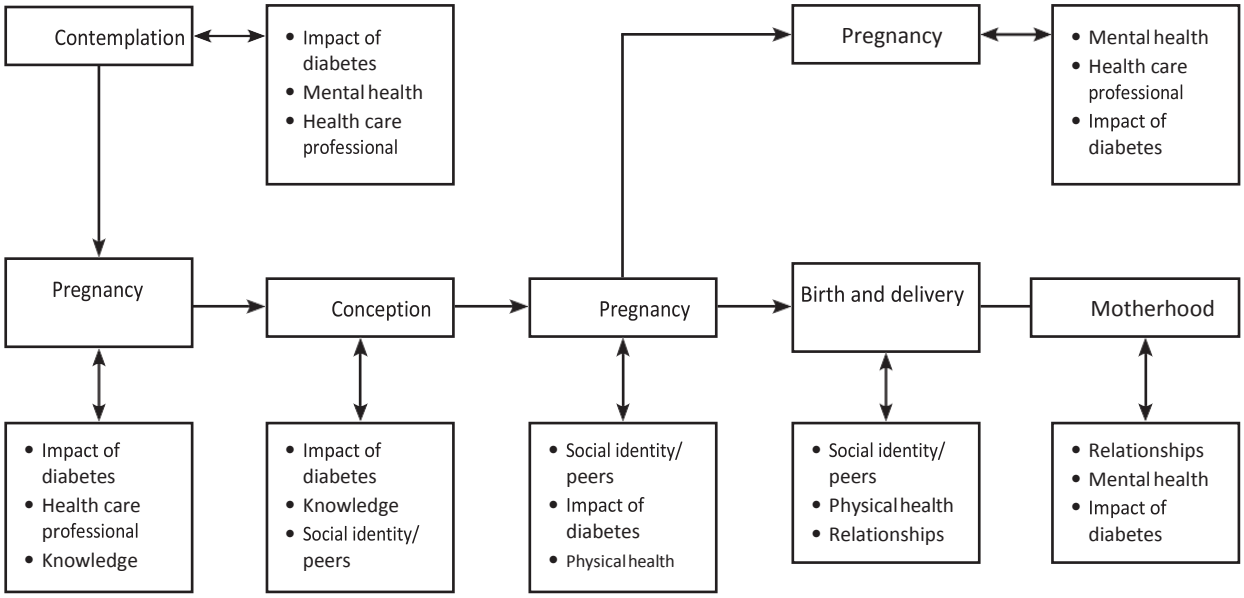
Relationships: Partner, Family and Baby (15% of text excerpts)**:** Relationships with significant others, including partner, family and baby, peaked in importance during 'motherhood'. At this stage, breastfeeding and the relationship between mother and baby was key.

Social Identity and Peer Support (13% of text excerpts)**:** Social identity and accessing peer support were critical in women feeling empowered about having the healthiest and most fulfilling experience possible. Reassurance was actively sought and this was highest during 'pregnancy'.

The codes for 'impact of diabetes' accounted for 19% of codes, with the 'mental health and emotional well-being' and 'relationships' codes being roughly equal and the most coded themes. The analysis of journey phase indicates that most of the women's interactions with DCO concerned the period of actual 'pregnancy', followed by 'motherhood' and 'contemplation' of pregnancy. However, themes are unevenly distributed across the journey, see Figure 1. For instance, the theme of 'balance and juggling' seemed most common when women were in 'contemplation' of pregnancy and in 'motherhood', but appeared less of an issue during 'pregnancy', although this theme was not one of the top three at any time point. Unsurprisingly, 'mental health and emotional well-being' issues peaked with the experience

of 'pregnancy loss'. Figure 2 depicts the three most common themes expressed at each phase of the journey.

Figure 2: Model of the Journey of Pregnancy



DISCUSSION AND CONCLUSION

This study identified seven possible, distinct phases of the pregnancy journey for women with type 1 diabetes and eight themes, evident to varying degrees within each phase. Across these phases, written interactions indicated shifting priorities and varying informational and emotional support needs throughout the journey. This indicates that women are seeking informal pre-pregnancy counselling and advice from non-mainstream sources, rather than through traditional healthcare pathways. This is unsurprising given that other studies have reported negative perceptions of health professionals when it comes to pre-pregnancy advice [7]. Connections with other women who have been or are currently pregnant appear to offer reassurance over and above that provided by healthcare providers.

The eight themes identified resonate well with previous studies that point to the challenges of balancing the demands of blood glucose management [8,12-14] and the challenge of

negotiating relationships with health professionals [12-13]. This study validates and adds to previous small-scale (N=7-15) studies with our larger sample (N=93) providing more robust data and highlighting specific themes and issues. 'Mental health and emotional well-being' were identified as a strong theme, with the aspect of diabetes-specific distress changing in focus from mother, to baby and back to mother again. This extends the work of Rasmussen and colleagues, which examined changes from pregnancy to post-natal experiences [7]. The changing nature of these issues experienced by women during the pregnancy journey suggests that one-off assessments of psychosocial issues may not be appropriate and that different assessment and approaches to facilitate coping at different time points may be required to reduce the negative impact of pregnancy on mental health and emotional well-being. A questionnaire focusing on both diabetes and pregnancy-related wellbeing has been developed [18] and offers the first opportunity to systematically consider the emotional impact of both pre-existing diabetes and pregnancy/motherhood.

Notwithstanding the large sample for a qualitative study, it is important to acknowledge that this analysis is based upon the 'conversations' of a somewhat select sample, that is, women seeking help via online sources, outside the normal private and public healthcare provision for diabetes and pregnancy. Although this study has the strength of identifying issues arising for women who may not be attending (or receiving the support they need from) traditional healthcare services, we do not recommend extrapolating these findings to all women with (type 1) diabetes.

Given that data were derived from naturalistic interactions with the DCO service, rather than via traditional research recruitment, we know little about demographic / clinical characteristics (e.g. age, diabetes duration, treatment regimen, pregnancy history) of the sample. In addition, the data analysed include as many as 44 references from a single woman over the entire journey from 'pre-pregnancy' to 'motherhood', to one-off interactions at a

single point in time. Therefore, this naturalistic sample is simultaneously longitudinal in some respects and cross-sectional in others. Further longitudinal research with more representative samples is needed to confirm or refine the model derived from these data. The key strength of this study is undoubtedly the quantity of data, with interactions analysed from 93 women, and 2,060 coded data points. We believe this to be the most comprehensive qualitative exploration of pregnancy in women with type 1 diabetes to date.

IMPLICATIONS/RELEVANCE FOR DIABETES EDUCATORS

These findings indicate that the provision of resources for women contemplating, planning or during pregnancy and early motherhood need to balance risk information with accounts of positive experiences and signposting to sources of peer support. If not, information about the risks and potential for poor outcomes may have a negative impact, with women less inclined to seek pre-pregnancy counselling. We recommend that information resources are: a) delivered via a variety of sources/media that are relevant, accessible and able to be revisited when needed; b) include accounts of real-life experiences, to ensure normalisation of the experience of pregnancy with type 1 diabetes; offer reassurance to reduce distress and anxiety; and ensure that a woman's own expertise and history in relation to their diabetes is respected and included in the collaborative development of management plans throughout the pregnancy journey.

While women with type 1 diabetes experience a pregnancy journey that appears similar to the standard pregnancy journey in terms of the seven phases identified, the eight themes suggest additional diabetes-specific challenges and greater risks to both physical and mental health outcomes among women with type 1 diabetes. Outcomes from this study suggest a high need for and acceptance of non-traditional health information sources and peer support for pregnant women with type 1 diabetes. The ability to augment and strengthen holistic care

for women during this journey is an exciting prospect with the potential impact yet to be fully realised.

Acknowledgements

We thank the women who shared their experiences online and enabled this study to be conducted. No external funding supported this research.

Conflicts of Interest

Helen Edwards is the founder and Chief Executive Officer of Diabetes Counselling Online, a not-for-profit organisation that provides free online counselling and support for people with diabetes. All other authors declare no conflicts.

Table 1: *Exemplar quotes relating to the eight themes identified across the pregnancy journey of women with type 1 diabetes*

Balance and Juggling	
Contemplation; *Participant 10*	*"the problem for me is getting my head around what I can and can't eat and understanding the GI [glycaemic index] system and just finding more motivation to stick to the diet, exercise. I still want to socialise with people without feeling abnormal."*
Motherhood *Participant 42*	*"I sometimes think that if I had just diabetes to concentrate on, I'd be more than capable, but when you add anything else (family, work, school etc) diabetes seems to be pushed to be the back. It seems it's always easier to make some excuse to put anything else first, even though I'm very aware that ignoring diabetes is only putting a lot of strain on my body, and that it will come back as one of many complications. It feels very overwhelming. And I've never learnt a way to deal with it."*
Healthcare Professionals (HCPs) and Medicalisation	
Pregnancy *Participant 34*	*"My scan is in a few weeks and I can't wait – It will be a big relief to have it done."*
Pregnancy *Participant 74*	*"I don't want to ask a health professional because they quote HbAIcs and targets like "under 7" which I know and am targeting – that doesn't mean it always happens!! I'd appreciate anything anyone can share who has been there, done that."*
Pregnancy *Participant 15*	*"I have just discovered that I am pregnant (7 weeks), not planned. I have seen an Endocrinologist once, and she put the scares up me."*

Pregnancy *Participant 78*	*"I have had diabetes for 20 years and am currently 5 weeks pregnant. My Endo won't see me because it's been over a year since my last visit, so I am seeing my GP Nov. 16 to get a referral. I am worried it will be too late as my control is not great."*
Pregnancy *Participant 29*	*"A lot of the time I feel I manage the diabetes myself, in that when I go to Endo, he does not really tell me anything that I don't already know"*
Pregnancy *Participant 15*	*"The Endo I saw this time was a lot better than the first one that I went to see. She actually said that I was doing a good job. I have to go back again next Wednesday"*
Pregnancy Participant 55	*"She seems reasonably happy with my levels and makes continual adjustments ….. However, I feel that I have had too many readings above 10 and that my baby will be harmed."*
Impact of Diabetes on Experience of Pregnancy	
Contemplation *Participant 12*	*"My partner and I are thinking about having a child in the next year or so. I'm concerned about my diabetes and the impact it would have on the child and myself during pregnancy / childbirth."*
Motherhood *Participant 60*	*"But after having my baby the wheels fell off and my control went a bit crazy. I was either hypoing or having highs."*
Motherhood *Participant 5*	*"I wonder whether my control is as tight as it should be, whether having at least one hypo a day is normal, whether I am going to end up with a long list of ghastly complications if I don't have "perfect control", what if I lose consciousness one day when I'm at home with the kids by myself... the list is endless."*
Motherhood *Participant 72*	*"I found pregnancy a real juggle with sugar levels. My levels would drop suddenly and I had some totally unexpected hypos, which landed me in hospital, but only for a few hours. I was really strict with my control which helped with good outcomes but it was hard work."*
Knowledge Seeking and Application	
Pregnancy Planning *Participant 24*	*"I'm wanting to start a family and I'm having trouble finding any information that doesn't make it sound like I'm trying to? be a horrible person to want to have a baby when I have diabetes."*
Pregnancy Planning *Participant 13*	*"I really want to get these [blood glucose levels] down as I want to be able to start planning a family but to do that my blood [glucose] levels need to be lower all the time."*
Mental Health and Wellbeing	
Pregnancy *Participant 79*	*"Has anyone had lack of control over their [blood] sugars during their pregnancy and still given birth to a baby without any abnormalities? I am 8 weeks and am starting to panic over sugar levels that refuse to stay in the*

	optimal range regardless of what I do (obviously I am doing the best I can and taking no risks). I get high days (over 10) and single high readings other days and I start to panic. Anyone out their feeling the same?"
Pregnancy *Participant 25*	*"I have been so stressed and racked with guilt whenever I have higher levels, and it has only been 3 weeks - I will be a nervous wreck by the end of the pregnancy!!!!)."*
Motherhood *Participant 36*	***"****I have always had a really positive outlook on life but, since having my daughter, I seem to be worrying about my health all of the time. But the whole thing could be psychological because I am worrying so much. I am just scared of the future; I'm scared of being sick and in pain and of dying early. There is nothing happening health wise that I am worried about right now though, I am just worrying about things that 'might' happen later on."*
Motherhood *Participant 61*	*"I don't know what is going on. I feel very depressed, crying a lot. I just feel I have no-one to talk to or understand. My husband is there but I feel he can't really understand what it's like to know that this isn't going away ever."*
Motherhood *Participant 66*	*"Sometimes I really don't care if I take the insulin, then I realise if I don't get my [blood] sugar under control I will not be around for my boys (they are 17 months and 3 years old)."*
Motherhood *Participant 36*	*"My health problems suck! :(I used to be so good at being happy and not letting my diabetes get in the way of my life but it really is getting in the way at the moment. My husband is getting sick of me being so emotional all of the time, but I am finding it really hard to deal with because my BGLs [blood glucose levels] are so crazy, and ever since having my daughter I seem to be a bit depressed in general."*
Physical Health: Mother and Child	
Motherhood *Participant 34*	*"I am trying really hard to rest and look after myself by exercising and eating well and I am trying to think very positively about the baby being OK and not having any problems."*
Motherhood *Participant 29*	*".. My Daughter was born at ……. weighing 7 pound 8 ounces - 50cm long. You will be pleased to know that I managed to get my wish and went into natural labour (before being induced) and had her naturally without any pain relief. It was a good feeling proving the Obs [obstetrician] wrong. She had one low blood sugar but as I had been expressing colostrum and freezing it since week 34 the nurses gave her some of that and it brought her levels back up."*
Relationships: Partner, Family and Baby	
Motherhood Participant 65	*"I have also had many joyous moments like when I gave birth to my kids, or when I got married"*
Motherhood	*"I love being a Mum. I find it really hard because I am so tired all of the time but I love it. I love being a Mum because of the happiness that I see in her*

Participant 36	*eyes. She is a great kid. I feel like she is a blessing (you know how the docs warn you that all of these things are going to be wrong with your baby because of your diabetes, but she turned out just fine). I love being proud of her achievements. I love cuddling and kissing her and knowing that I am her mum."*
Social Identity and Relationships with Peers	
Conception Participant 68	*"So, on I plod feeling like a pin cushion. Has anyone else been on this roller coaster and come out the other side smiling? Will I get to be a real mum (I am already a step mum) or more importantly will I get to create another little person with my darling husband who I love so much?"*
Pregnancy *Participant 69*	*"Anyway, I hope it's going well so far - when are you due? I'd love to hear how you have gone so I know what to look forward to (or dread!!) I am calling out for all the support I can get from here. The last week has been very emotional for me."*
Pregnancy *Participant 79*	*"Has anyone had lack of control over their [blood] sugars during their pregnancy and still given birth to a baby without any abnormalities? I am 8 weeks [pregnant] and am starting to panic over [blood] sugar levels that refuse to stay in the optimal range regardless of what I do."*

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CONTEXTUAL STATEMENT STUDY 2

In the following chapter I will present the development of the prototype Contemplating Pregnancy in Diabetes Communication Support Questionnaire, and discuss the rationale for this, followed by describing the 5-phase questionnaire development process, including a pilot study. I then present the analysis of the Contemplating Pregnancy in Diabetes Communication Support Questionnaire, based on a small cognitive interview study, followed by basic descriptive data and psychometric analysis.

CHAPTER 4: DEVELOPMENT AND ANALYSIS OF A CONTEMPLATING PREGNANCY IN DIABETES SUPPORT QUESTIONNAIRE

PREAMBLE

In the previous chapter, I presented a published paper detailing the results of a thematic analysis of online diabetes counselling records. This analysis supported evidence from the literature review, that preparation for pregnancy for women with type 1 diabetes is key to a healthy pregnancy and baby. It also supported the fact that negative communication about pregnancy can actively prevent women from attending pre-pregnancy counselling.

In this chapter, I have therefore chosen to focus on the Contemplation phase of the pregnancy journey and the significant gaps in women accessing pre-pregnancy counselling. The Contemplation phase appears to be an important place to present information about pregnancy planning. This chapter builds on the study 1 analysis and the evidence from the literature review, developing a Questionnaire to support communication around preparedness for pregnancy during the Contemplation phase. The three major themes of importance to women identified in the Contemplation phase in study 1, were the impact of their diabetes on pregnancy; their mental health; and their relationships with health care professionals. These formed the basis for development of items for the Questionnaire.

The Questionnaire aims not only to facilitate the content of these discussions, but to encourage shared decision making, with the focus of the conversations being led by the woman with type 1 diabetes' responses to the items. The Questionnaire notes for health care professionals recommend that women complete the items prior to a consult, and that the health care professional and the woman with type 1 diabetes then consider each response together, to consider where support and intervention may be needed. The Questionnaire is as much about determining where the health care professional might need to make changes to supports and services, as it is about the personal, social and psychological resources of the

woman with type 1 diabetes. It is intended to be used in a narrative way, rather than as a scored assessment tool, and is very much about equally supporting the process of communication and the content of consultations.

In this chapter data are presented that illustrate the items used in the Questionnaire were overall relevant and easy to understand for pilot participants. Some changes were recommended during the cognitive interviews. There was high internal consistency evident on Scale 1 items, and low-moderate internal consistency shown on Scale 2 items. While outside the scope of this PhD, the prototype Questionnaire is now ready for testing in a larger cohort of women.

AIM OF THE STUDY

The primary aim was to use the model of the journey of pregnancy and key themes presented in study one, to develop a questionnaire to support communication about pregnancy for women with type 1 diabetes during the Contemplation phase. A secondary aim was to identify and refine potential problems in the Questionnaire items, through a pilot survey.

INTRODUCTION

As previously stated, it has been estimated that a person with diabetes only spends three hours per year with their health care professional. For the remainder of time they are managing their own condition (Chatterjee et al., 2018). Type 1 diabetes is frequently documented as a challenging condition to live with, and is an ever-present aspect of the person's life (Alzaid, 2014). The tasks required are reported as repetitive, sustained, and take valuable time from each day, often impacting on the person as well as their family's daily lives (Alzaid, 2014; Fisher et al., 2012; Kreider, 2017; Linden et al., 2016; Polonsky et al., 2005). The role of the health care professional is to offer their knowledge and expertise to support the person with type 1 diabetes to make informed decisions, but it is the themselves

who is ultimately responsible for daily diabetes management decisions and choices (Alzaid, 2014).

For many women with type 1 diabetes of child-bearing age, along with all of the usual diabetes management and health-related needs discussed within these three hours per year, is the need for provision of pregnancy information. This adds substantially to the logistical challenges. Health care professionals are often burdened by the extent of items to work through during consultations (Berg & Sparud-Lundin, 2009). This includes helping women of child-bearing age towards the acquisition of knowledge about the need for pre-pregnancy counselling, and an understanding about the desirable health-related behaviours required for the pregnancy journey (Endres et al., 2004). With Contemplation of pregnancy potentially lasting many years, encouraging pregnancy preparedness and supporting women's ability to maintain the desirable behaviours needed across the pregnancy journey, has been reported to be important. In chapter 2, I raised the issue of developing optimism and self-efficacy, adequate social supports, access to knowledge, and positive wellbeing, as all being required to enable this to occur (Edwards et al., 2016; Rasmussen, 2012).

A number of qualitative studies (Berg, 2005; Berg & Honkasalo, 2000; Berg & Sparud-Lundin, 2009; Linden et al., 2016; Rasmussen et al., 2015; Sparud-Lundin & Berg, 2011) report that self-efficacy and the ability to maintain desirable health related behaviours across the pregnancy journey, depend on each woman's personal identity, their approach and beliefs about pregnancy, and their social, psychological and personal resources. Health care professionals working with women with type 1 diabetes in pregnancy have a specific responsibility to not only ensure the best chances of a healthy baby, but also to support women to feel optimistic that they can indeed have a healthy pregnancy. Therefore, health literacy on the women's part and communication skills on the part of the health care professional, are important (Berg, 2005).

The relationship between health care professionals and their clients, and their personal style of communication, have been shown to be central during diabetes consultations. A RCT (Skinner et al., 2008) examining the DESMOND programme for diabetes, aimed to determine whether differences in the amount of time diabetes educators spoke during a diabetes self-management education programme, affected people's beliefs about diabetes. They found that the least amount of time that the diabetes educator was talking during a session, thereby encouraging more two-way interactions between people with diabetes and health care professionals, related to the magnitude of change in participants' reported beliefs about diabetes. They found that the least amount of time that the diabetes educator was talking during a session, the greater the change in participants' beliefs about their diabetes. Those centres who reached targets for interactivity for three sessions, had individuals who reported a greater increase in the perceived seriousness of diabetes ($t=2.49$; $P< 0.007$).

As presented briefly in the literature review in chapter 1, in relation to diabetes and pregnancy consultations, a thematic analysis (Risa, 2011) studying the communication patterns between midwives and women with diabetes, found that those communication patterns usually adopted by the midwives, seemed to reduce the opportunities for the women with diabetes to openly discuss any concerns. Their analysis was based on the following questions: (1) who talks and to what degree? (2) What are the topics discussed and who is the initiator? and (3) What characterises the dialogue in the consultations? They found that the midwives took up 66–81% of the talking time during consultations, compared with just 24–56% for the mothers. This showed that with the exception of three consultations, the midwives had the greatest number of speaking turns and used the most words. Bearing in mind this could be due to time restrictions and the need to address particular topics in midwifery consults, the midwives also spoke for longer periods of time, especially where they had information that needed explanation or teaching. The most common topics discussed

related to the health of the mother, which was most often initiated by closed questions from the midwife. This seemed to prevent the mothers from joining in with the conversation. The second most commonly discussed topic was in relation the baby's health, with the midwife asking whether the mother could feel her baby's kicks. Where the mother was using insulin, topics about diabetes management were included regarding hypo and hyperglycaemia, changes in insulin doses and management during the birth and the post-natal period. Discussion about breastfeeding and preparation for breastfeeding was also initiated by midwives. The topic of the timing and mode of the birth was more commonly introduced by the mothers, especially after 32 weeks of pregnancy. This topic related to questions about procedures, routines about the birth and hospitalisation, and why they might be required to undergo induction. The researchers suggest that greater openness to the emotional and psychological aspects of pregnancy should be included during consultations. In particular, the use of closed questions by the midwives, prevented a mutual exchange of information and understanding. In order to understand the woman's concerns, the authors recommend a person-centred approach, using open ended questions (Risa, 2011). This represents an issue with the broader systems in which midwives operate and reinforces the need for multidisciplinary teams in pregnancy and type 1 diabetes, in order to allow for a breadth of opportunities for provision of information and support, across a range of topics.

A meta-synthesis study (Forde et al., 2016) of the experiences of pre-pregnancy counselling for women with type 2 diabetes, found that the way health care professionals approached a discussion about pregnancy and the need for pre-pregnancy counselling, influenced the probability of women taking action. Whilst this was in relation to type 2 diabetes, the findings are consistent with other studies reported in this thesis, that included type 1 diabetes. Many women reported that they did not attend pre-pregnancy counselling because they were never told about why it was necessary. The information about pre-pregnancy counselling

was often given to the women in a disorganised, unplanned manner, meaning that they might have conceived before this information was provided to them. Some women felt that health care professionals did not think about their reproductive needs, or did not offer supportive information about pregnancy or pre-pregnancy counselling, due to biased views about their age or because they were obese. As in other studies, some women reported that they did not engage in pre-pregnancy counselling because they felt that they may have been actively discouraged from trying for a baby. Others felt that the relevance of pregnancy information would be enhanced if it highlighted the potential benefits of pre-pregnancy counselling - for both themselves and their babies. In this study, many health care professionals identified limitations in the health care system as impacting on their delivery of pre-pregnancy counselling. These included the complexity of relationships between primary and specialist care providers, the need to ensure that information across multi-disciplinary teams is consistent, and resource constraints (Forde et al., 2016).

The complexity of the health system is therefore important to address in relation to pregnancy and type 1 diabetes services. Women with type 1 diabetes have been reported as feeling like messengers between their various health care professionals during pregnancy (Berg & Sparud-Lundin, 2009). It is suggested a range of health care professionals can be involved in delivery of pre-pregnancy counselling for women with type 1 diabetes. This includes primarily an Endocrinologist, a General Practitioner, Diabetes Educator, or Obstetrician (Morrison et al., 2018). As such, there is a role for both general practice and specialist diabetes health care professionals in delivering information about preparedness for pregnancy and the importance of pre-pregnancy counselling. Further, midwives offer a perhaps untapped opportunity to coordinate and disseminate information about pregnancy and type 1 diabetes. A number of studies have shown that if pregnancy services are not coordinated, women may experience distrust and uncertainty about the healthcare providers

knowledge and competence (Rasmussen, 2012). A more coordinated, multi-disciplinary approach to pre-pregnancy counselling could offer more cohesion and prevent the current feelings of fragmentation experienced by some women with type 1 diabetes. This would require work to explore the best manner of service linkage and how to reduce doubling up of resources and reduce strain on pregnancy and diabetes services.

Supporting the need for coordination of pregnancy services, a small exploratory study into women's perceptions of being pregnant with type 1 diabetes (Lavender et al., 2010) identified three main themes - relinquishing personal control, pregnancy overshadowed by diabetes, and haphazard preconception care. Women who were pregnant reported high levels of disruption to their daily lives, and this was stressful; and a sense of relinquishing personal control to health care professionals. This relinquishment was in general, anticipated by the women and accepted as important to ensure the best outcomes. If the focus was entirely on diabetes management however, this could increase anxiety. During this study, all pregnant women expressed disappointment that during their hospital visits, the over-riding focus was on diabetes management, rather than the pregnancy itself. Rather than feeling reassured by the focus on diabetes during antenatal visits, this made some women more anxious (Lavender et al., 2010).

In summary, these observations suggest that discussions about pregnancy with women with type 1 diabetes should include a focus on the pregnancy itself and what to expect, rather than just concentrating on diabetes management. It is suggested in the literature that routine care is the ideal place to present this information, albeit not at a time that may be seen as irrelevant to the woman. Multi-disciplinary teams must be coordinated and resourced to deliver pre-pregnancy counselling information, and communication between women with type 1 diabetes and their health care professionals needs to be positive, inclusive, and empowering.

TOOLS AND INSTRUMENTS USED IN DIABETES CARE

Historically, the use of survey tools in health care was aimed at assessing patient-related outcomes, particularly those concerning functional ability (Farnik & Pierzchała, 2012). More recently, researchers have focused on clinical assessments that relate to positive health concepts, such as quality of life (Farnik & Pierzchała, 2012). Many aspects of health and wellbeing can be measured via both generic and/or disease-specific tools, depending on the research questions and purpose (Farnik et al., 2010). Generic instruments assess a wide range of constructs, and can be applied to a wide range of health conditions, as well as in healthy populations. Disease-specific tools have the benefit of including particular aspects of the disease or condition itself, increasing their relevance to health care professionals and respondents. With disease-specific tools, the focus is more targeted, so that they have the best potential to being responsive to changes in health. They also offer a more detailed and accurate assessment of the perspective of the respondents (Farnik et al., 2010).

In this thesis, I am interested in developing a tool that will primarily support communication about the importance of pre-pregnancy counselling for women with type 1 diabetes; and which will help to develop preparedness for pregnancy. The aim is not to measure or assess the woman and her behaviour. Rather, it is to support both the content and process of such discussions. In my exploration, the most commonly used tools in health and in diabetes however, are for measurement and assessment of clinical outcomes, health related behaviours and physical and psychological status, rather than to support communication. There are a number of diabetes-specific measurement and decision making tools available (Eigenmann, Colagiuri, Skinner, & Trevena, 2009) ranging from those that consider one aspect of health such as diabetes distress, through to quality of life and diabetes management skills. There are also generic tools used in diabetes care, to assess constructs including health-related quality of life, mental health and wellbeing. The purpose, quality and applicability of

such survey tools reportedly varies widely (Eigenmann et al., 2009). The ultimate aim of this Questionnaire however, is not to measure an outcome, or a change in outcome, but instead to encourage a conversation. None of the currently available tools described below are particularly relevant for this purpose, because they are not designed for the primary purpose of encouraging a conversation, nor indeed, a conversation about pregnancy.

Selecting the appropriate health tool can be difficult and time-consuming. Factors in choosing a particular tool include consideration of purpose, concept, readability, burden to subjects, the cost associated with its use, and the measurement properties of the instrument (Eigenmann et al., 2009). An Australian study (Eigenmann et al., 2009) identified 37 available diabetes specific tools. The study employed a structured semi-systematic literature review and consultation with experts. This was followed by development of inclusion criteria and a formal, purpose designed, systematically derived Appraisal Checklist. This evaluated the identified tools for relevance, validity, reliability, responsiveness to change, burden, feasibility and acceptability. Of the 37 tools, the authors found that three tools measured diabetes knowledge and understanding, five diabetes self-management, seven self-determination and 22 psychological adjustment, respectively. Although numerous tools were identified, only a small number met the rigorous psychometric appraisal of the study criteria. Issues which limited selection included the suitability of the tools, adequacy of psychometric testing for the intended purpose, burden on the respondent and feasibility. No diabetes and pregnancy specific tools were identified, nor tools aimed at supporting communication in diabetes care (Eigenmann et al., 2009).

A systematic review (El Achhab et al., 2008) on health-related quality of life for people with diabetes, identified 16 instruments which met their inclusion criteria: appraisal of diabetes scale (ADS); audit of diabetes-dependent quality of life (ADDQoL); diabetes-39 (D-39); diabetes care profile (DCP); diabetes distress scale (DDS); diabetes health profile

(DHP1, DHP-18); diabetes impact measurement scales (DIMS); diabetes quality of life measure (DQOL); diabetes quality of life clinical trial questionnaire-revised (DQLCTQ-R); diabetes specific quality of life scale (DSQOLS); elderly diabetes burden scale (EDBS); insulin delivery system rating questionnaire (IDSRQ); quality of life with diabetes questionnaire (LQD); problem areas in diabetes scale (PAID); questionnaire on stress in diabetic patients-revised (QSD-R) and well-being enquiry for diabetics (WED) (El Achhab et al., 2008). Again, no diabetes and pregnancy specific tool was identified nor any communication support tools.

A second systematic review (Speight, Reaney, & Barnard, 2009) on quality of life measures used in diabetes identified the ten instruments most frequently used to assess 'QoL', but concluded that only three of these tools actually do so - the generic World Health Organization Quality of Life (WHOQOL) the diabetes-specific Diabetes Quality of Life (DQOL) and Audit of Diabetes-Dependent Quality of Life (ADDQoL)]. Seven instruments were found to more accurately measure health status [Short-Form 36 (SF-36), EuroQoL 5-Dimension (EQ-5D)], treatment satisfaction [Diabetes Treatment Satisfaction Questionnaire (DTSQ)] and psychological well-being [Beck Depression Inventory (BDI), Hospital Anxiety and Depression Scale (HADS), WellBeing Questionnaire (W-BQ), Problem Areas in Diabetes (PAID)]. The researchers concluded that no single measure can suit every purpose or application and that when selected inappropriately, any conclusions are fundamentally flawed (Speight et al., 2009).

A tool aiming to measure three key aspects of diabetes self-management: knowledge of a skill, confidence in being able to perform that skill, and preparedness to implement the skill; has been developed, using a mixed methods design (Mbuagbaw, Aronson, Walker, Brown, & Orzech, 2017). The authors state this tool is novel, in that no other available diabetes measurement tool includes all three aspects. However, whilst it includes the construct of

preparedness, it is intended for use in relation to general diabetes management and does not provide information in relation to pregnancy preparation; nor does it support communication specifically. Preparedness was included in this tool because possession of knowledge, and the confidence to implement a skill, require the preparedness to act. Each dimension was seen as important for successful diabetes self-management (Mbuagbaw et al., 2017).

WHY DEVELOP A PREGNANCY AND DIABETES COMMUNICATION SUPPORT QUESTIONNAIRE?

Generally, tools in health are developed to measure or understand phenomena that are thought to exist because of our theoretical understanding of the world, that cannot be directly assessed (DeVellis, 2017). For example, anxiety and depression are constructs that are widely understood as explanations for behaviour that can be seen, but they are not the behaviours themselves (DeVellis, 2017). The development of this prototype Questionnaire was centred on the premise that pre-pregnancy counselling for women with type 1 diabetes might be enhanced through the incorporation of a communication tool, aimed at better understanding the construct of women's preparedness for pregnancy, and supporting the process of communication between women with type 1 diabetes and their health care professionals during contemplation of pregnancy. This is based on the body of literature presented here, indicating negative communication and untimely pregnancy information can actively prevent women with type 1 diabetes from attending pre-pregnancy counselling. It is further based on findings that timely and positive communication, shared-decision making, acknowledging women's expertise in their own type 1 diabetes and focusing on pregnancy itself alongside diabetes targets, might increase women's uptake of pre-pregnancy counselling. As shown, such tools are often used in health, and in diabetes. However, I was unable to uncover an existing tool that specifically addressed the aims of this thesis. Therefore, this study focuses on the development of such a tool.

The work is informed by The Diabetes Australia Position Statement on Language in Diabetes ("Diabetes Australia Position Statement on Language,") which states that the way language is used during interactions – both verbal and written – reflects and shapes thoughts, beliefs and behaviours. This statement suggests that 'language has the power to persuade, change or reinforce beliefs, discourse and stereotypes – for better or for worse; and that words do more than reflect people's reality: they create reality' ("Diabetes Australia Position Statement on Language,"). The position statement recommends the use of language in diabetes care that encourages positive interactions and positive outcomes for the person with diabetes, once they leave the appointment and pursue their daily lives ("Diabetes Australia Position Statement on Language,"). Further, it is suggested that for people with diabetes, feelings of failure, frustration and self-blame are common consequences of unrealistic expectations and that many people might cease confiding in their health care professional(s) or family members to avoid judgmental or negative responses ("Diabetes Australia Position Statement on Language,").

Another consideration in the development of the Questionnaire, is the thinking emanating from health outcomes research. This is increasingly concerned with consumer evaluations about clinical effectiveness of care (Eigenmann et al., 2009). In diabetes, relevant health outcomes have been shown in numerous studies to include not only physiological measures, but also subjective factors, such as disease self-management burden, social functioning, relationships, quality of life, emotional health and physical functioning (Eigenmann et al., 2009; Fisher et al., 2008; Fisher et al., 2012; Gonzalez et al., 2011; Polonsky et al., 1995). These subjective factors are of particular importance for people with diabetes because the condition is primarily self-managed, and self-management regimens affect all aspects of daily life (El Achhab et al., 2008).

Supporting the importance of effective communication in pregnancy and type 1 diabetes, a systematic literature review (Elena-Daniela et al., 2015) found that in diabetes care, in general, an effective relationship between health care professional and the person with diabetes, requires the health care professional to utilise twelve crucial abilities. These are empathy, use of open-ended and closed-ended questions, active listening, use and identification of non-verbal cues, keeping silent, time management, summarizing, use of common language, clarifying responsibilities, action planning, evaluation of the patient's understanding, and making decisions together with the patient (Elena-Daniela et al., 2015). These abilities fit with many of the recommendations in the literature in relation to effective communication in pregnancy and type 1 diabetes. Accordingly, when these abilities are part of the health care relationship, the person with diabetes is an active participant, and the relationship is based on a common ground of received information, and his/her own set of values (Elena-Daniela et al., 2015). This aligns well with person-centred care, where an exploration of the person's condition, assessing them holistically within their psychosocial context, establishing a common ground from which to work together, developing secondary and tertiary prevention interventions, consolidating the relationship, and having a realistic approach to goals and outcomes, are all valued (Elena-Daniela et al., 2015).

The evidence presented so far, has shown that while women with type 1 diabetes are often experts in their own type 1 diabetes, pregnancy brings with it a new set of challenges and complexities, requiring support from health care professionals across the journey. However, women might have been given pregnancy risk information that has made them wary about approaching health care professionals about pregnancy; and/or information might have been given at inappropriate times. Pre-pregnancy counselling is consistently recommended as the major intervention supporting positive pregnancy outcomes. Therefore, health care

professionals are a primary resource to assisting women with type 1 diabetes to develop preparedness for pregnancy.

THE PROCESS OF TOOL DEVELOPMENT

Thinking clearly about what to include in a tool of any type requires proper evaluation of the construct of interest (DeVellis, 2017). It is essential to properly understand what this construct means, what questions might identify relevant aspects of the construct, and how-to best measure these. The boundaries of the scale need to be clear, so that the items do not relate to constructs that are broader than the one of interest. In other words, it must measure exactly what it sets out to measure, and be reliable and consistent in its approach. A theoretical basis must also be considered (DeVellis, 2017). The overriding objective of developing any tool is to translate the researcher's needs for information, into a set of specific questions or items, that respondents are willing and able to answer accurately (Farnik & Pierzchała, 2012). Following study one and the literature review, the components of both the desirable health-related behaviours for pregnancy in type 1 diabetes; and the personal, social and psychological resources needed for the journey, were determined to relate to the construct of 'preparedness for pregnancy'. The challenge was to determine what particular items would relate specifically to this construct, and how to best ask questions that women with type 1 diabetes would be prepared to answer and could answer accurately.

The process of tool development in this study was based on a multistage procedure (DeVellis, 2017), which included the preliminary phase of developing the initial concepts for items/questions, defining the reasons for creating the tool, identification of consumers or special groups to which the tool is addressed, identification of needs and operationalization of variables. Next there was a process of item development, followed by pilot testing: assessment for feasibility, comprehension, ease of use, usefulness of the tool, context of the

research; and finally, evaluation: the validation process, including reliability, reproducibility, internal consistency and responsiveness (Farnik & Pierzchała, 2012).

Further consideration in the development of the Questionnaire related to the need for assessment of reliability. Reliability is a critical aspect of any tool. Reliability coefficients of 0.70 are generally acceptable for measurement in a study of a group of people in a health related setting (Eigenmann et al., 2009). Validity assesses the extent to which a tool measures what it claims to measure. As well as these 2 aspects, it is essential that a tool is acceptable to the intended target group, to avoid distress related to the completion of the items and facilitate a higher response rate. A number of indicators of acceptability to respondents, including the time taken to complete the tool, the number of participants who find the tool difficult or distressing to complete, as well as rates of refusal and missing responses, are easily able to be noted (Eigenmann et al., 2009). In this case, the pilot study included a basic process of reliability and validity testing, including cognitive interviews to determine acceptability to the target group.

METHODOLOGY

At the beginning of development of items for the Questionnaire, according to the methods of tool development discussed here, a detailed, 5-phase scale development process was undertaken (DeVellis, 2017) (see Figure 1). This included item generation; development of structure and format for measure; expert review; item refinement and pilot testing and analysis. Face and content validity were tested using cognitive interviews and basic scale reliability analysis. Ethics approval was granted by the University of Adelaide.

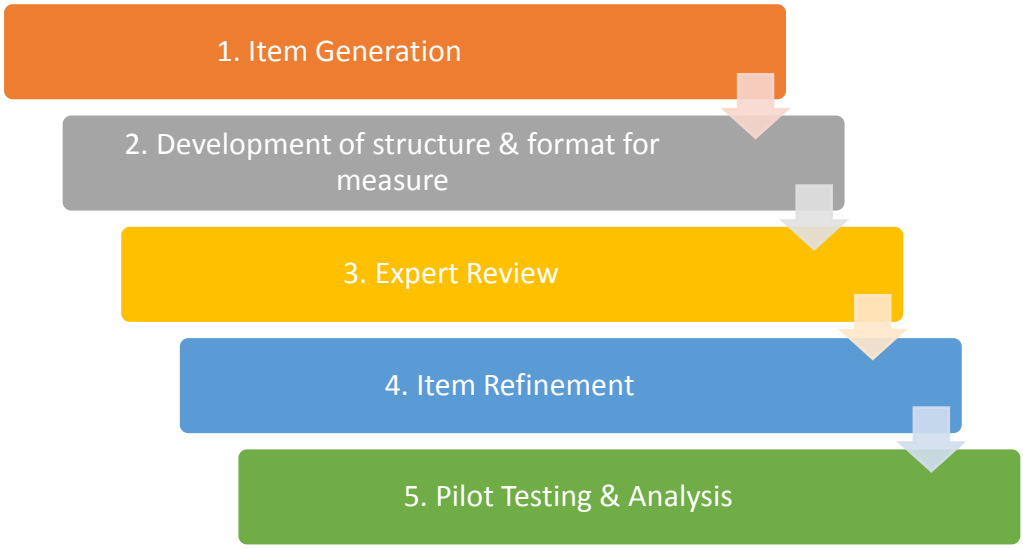


Figure 1: Questionnaire Development process

1. Item Generation

Given the construct of 'preparedness for pregnancy' has been defined in this thesis as having 2 related parts – 1) desirable health-related behaviours for pregnancy with type 1 diabetes; and 2) the personal, social and psychological resources needed for the journey, I considered both of these aspects as a framework for item generation. To begin item generation for the Questionnaire, I firstly considered the key points discussed in the literature review in chapter 1, including the importance of women's knowledge about diabetes and pregnancy, their knowledge about and access to, pre-pregnancy counselling, and their health care, family and peer support.

I then reviewed the Australian guidelines for management of pregnancy and diabetes (McElduff et al., 2005) to consider what desirable health-related behaviours needed to be included as items. Finally, I reviewed the three major themes identified during the Contemplation phase of the pregnancy journey in chapter 3. This involved re-reading the extracts from the counselling records included in study 1 and relating these extracts back to the top three themes during Contemplation, as follows:

1. Impact of diabetes – women's knowledge about diabetes and pregnancy and their past and current diabetes management/impact;
2. Women's mental health; and
3. Their relationships with health care professionals.

I then developed an overarching range of potential items. In reading the counselling records and considering the literature and guidelines for pregnancy and diabetes in Australia (McElduff et al., 2005), I was interested in including firstly, items that related to women's diabetes and general health status, connecting to the desirable health-related behaviours needed for the journey. This included considering items in relation to diabetes history, the course and length of time living with diabetes, major events such as severe hypoglycaemia, diabetes complications, current diabetes management, and access to diabetes management tools and resources.

Secondly, I considered the personal, social and psychological resources available for the journey. This included items in relation to women's beliefs about type 1 diabetes and pregnancy, their health-related behaviours and their social environment. Given the importance of mental health and social support, women's mental health history was included, in particular, any experience of diabetes specific distress, depression, and burn out. Items related to support included partner, family and peers; and access to diabetes and pregnancy services, other diabetes health care professionals, and previous interactions with them. Pregnancy history, any prior pregnancy loss, difficult prior pregnancy experience, number of pregnancies and/or difficulties getting pregnant, were included. Finally, women's life responsibilities, juggling competing priorities and finding balance, were determined to be important themes in both the literature and study one – so these were also developed into potential items. Along with key points from the literature, this unique insight developed through study one contributed to the development of the final item framework for the

Questionnaire. Following this process, a table was drawn up to connect the key themes from the literature and study one, with the items finally included in the pilot Questionnaire, and how these mapped onto the counselling records examined in study one.

Table 1: Framework Development

THEMES DEVELOPED FROM LITERATURE & STUDY 1	**ITEMS & PRE-SCREENERS FOR PILOT QUESTIONNAIRE**	**STUDY 1 – women's words and key issues**
1) Beliefs and knowledge about diabetes and pregnancy Current beliefs and knowledge about diabetes & pregnancy Gaps in knowledge The ways that knowledge relating to diabetes and pregnancy is used and gained; understanding what this knowledge is and where it comes from Possible future needs for knowledge	1.Talk with my diabetes care team about what steps to take in preparing for pregnancy 2.Use contraception until I talk with my diabetes team about planning for pregnancy 3.Talk with my health care team about the target for my HbA1c before I start planning for pregnancy 4.Take high dose (5mg) folic acid prior to and during my early pregnancy [from and up to the time advised] 5.Stop or change any potentially harmful medications I may be taking before pregnancy, as recommended by my doctor 6.Manage my diabetes with the latest technology available such as insulin pumps and continuous glucose monitors	Self-Efficacy Confidence Level of Knowledge Desire for Knowledge Being a mother Unanswered questions The unknown Seeking information Making the decision Being responsible Having a plan Desire for "normal" delivery Wanting my baby to be safe Hurdles to jump Medicalisation Taking control

	7.Have routine checks for diabetes complications such as retinopathy and kidney health 8.Have a fitness assessment at my local gym or health centre 9.Even if I have already had a baby, see my diabetes team for pre-pregnancy care 10. Reduce my alcohol consumption to the recommended safe drinking levels for women when planning a pregnancy, and to zero once pregnant 11. Work with my health care team to achieve healthy blood pressure levels 12. See my doctor for a review of all medications I am taking, including complementary medicines and supplements 13. Discuss a healthy exercise and eating plan with my diabetes team 14. Speak with my health care team about how I am feeling about my diabetes, and any concerns I have about how it may affect pregnancy	Becoming and being a mother Having a plan
2) Impact of Diabetes and Current Health/Diabetes Management Current health and diabetes status	• Do you think pre-pregnancy planning and care is important for women with diabetes?	Enormous effort Yearning for a child Trying to be patient Out of my hands

Impact of current diabetes management on wellbeing Current need for changes to management	• Have you ever been pregnant? If so, how many times? • Were any of your prior pregnancies planned? • Have you ever had diabetes during any of your pregnancies? If so, how many times? • Do you have any biological children? If so, how many? • What is your age? • Have you ever had diabetes during the time you were planning a pregnancy? • What type of diabetes do you have? • When were you diagnosed with diabetes? • Do you know your most recent HbA1c? If so, please select from the following • Have you experience hypoglycaemia (low blood glucose)? • Do you monitor your blood glucose? If so, how are you monitoring it (e.g. finger pricks or continuous glucose monitoring) • How often do you monitor your blood glucose each day? • Do you know if you have any of the following	Taking control Medicalisation Difficulty trying to conceive Constant Burden Sudden changes in control Competing demands A juggling act Unpredictability IVF impact The battle for control Unplanned Pregnancy - Is my baby ok? Fertility beliefs Lack of access to technology

	diabetes related complications? Please select all that apply • Are you having regular checks for the following diabetes complications? Please select all that apply • How are you currently managing your diabetes? Please select all that apply. • What is the makeup of your household? • Do you live in a rural or regional area? • Have you ever visited with a diabetes and pregnancy clinic or specialist? 24. I would feel confident about managing diabetes during pregnancy 26. The focus on my diabetes would make it hard to have a positive pregnancy experience	
3) Current mental health and wellbeing Fear and anxiety around becoming a mother Experience of both positive and negative emotions, generally and diabetes specific	15. Looking after my emotional wellbeing and mental health would be just as important as caring for my physical health 16. I would worry about changes to my diabetes management during pregnancy 17. I would worry about the impact the effort of managing	Self-doubt Guilt Concern for baby General Anxiety Hypo Anxiety Seeking constant reassurance Diabetes Distress

Experience and impact of mental health history in relation to diabetes Confidence about becoming a mother	diabetes during pregnancy would have on my loved ones 18. I would worry about the impact of my diabetes on my baby 19. It would be too demanding to achieve blood glucose levels within the target range before conceiving 20. It would be too demanding to maintain target diabetes management throughout pregnancy 21. I might not be able to continue my daily work or other activities when managing diabetes and pregnancy 22. I would be overwhelmed by all the things I need to do to plan and prepare for pregnancy	Barriers and Hurdles Feeling relief from scans Conflicted feelings Worry about hypos After Pregnancy Loss - Futility: What was the point? Devastation, feeling blamed, blaming diabetes, loss of caring Developing Hope Positive Thinking Feeling broken Self-belief Hopelessness Depression Fear Worry Feeling alone Diabetes Burn Out A juggling act Mixed emotions Caring for self Finding balance Joy of being a mother Doing my best

		Anticipation and excitement Using my skills, being competent Making decisions
4) Relationships and support from Health Care Professionals, Partner, Family and Peers Relationships with significant others including partner, family, peers and Health Care Professionals and whether these are positive, negative experiences If there is a perceived lack of support from any of these sources Relationships and connections with peers - development of a social identity Expectation of support around pregnancy in the future from Health Care Professionals Impact and experience of medicalization Expectations and/or experience in seeking	23. Being connected to other people with diabetes via social media and other websites would be helpful for my wellbeing 25. In general, I could be open with my health care team about any struggles I have with diabetes and not feel judged 27. My family would be supportive of my desire to have a baby 28. My family may want to be too involved in my diabetes management during pregnancy 29. I already have a team of health care professionals who understand diabetes and pregnancy to support me when ready 30. I might feel isolated from people who understand what is needed in managing diabetes and planning a pregnancy 31. I would use diabetes related websites and social media groups for information and support about pregnancy and diabetes	Seeking reassurance Barriers to medical care Lack of understanding Disengagement from Health Care Professionals Unrealistic advice Impossible targets They don't understand Need for good HCP support Battling it together It's his baby too Relationship tension Family support A fine line Judgement Someone like me Genuine understanding Mutual support Positive Role Modelling Sharing the journey

reassurance from these sources of support.	32. I would use general pregnancy websites and resources for information and support 33. Being connected to other women with diabetes who have been through pregnancy would be important to me	Reassurance Increased Motivation[1]

The next stage of item generation was to consider predictors and barriers to women with type 1 diabetes attending pre-pregnancy counselling. With the guidance of my primary supervisor and a statistician, I undertook consideration of the factors that support or prevent women with type 1 diabetes in attending pre-pregnancy counselling. This assisted me later with the process of analysis of the usefulness and reliability of the items to include in the Questionnaire. In particular, determining whether the items in the pilot Questionnaire were scoring in a way that reflected these predictors and barriers. For example, if women of an older age in my pilot were more likely to have knowledge about the importance of pre-pregnancy counselling, or whether women in rural locations had less access to pre-pregnancy counselling. This was important to consider therefore, in the development of items.

Predictors highlighted in the literature included: women of an older age, those living in an urban location, longer duration of diabetes, with a lower HbA1c, type 1 diabetes, and first pregnancies (Abell et al., 2016; Colstrup, Mathiesen, Damm, Jensen, & Ringholm, 2013; Aoife M. Egan, Danyliv, Carmody, Kirwan, & Dunne, 2016). These predictors were demonstrated in a prospective cohort and cost-analysis study. The study designed, put into practice, and evaluated, a regional pre-pregnancy care programme for women with type 1 and

[1] Table 1 depicts the themes and description of themes from study 1, as related to the items for the pilot Questionnaire and the women's words taken from the counselling records in study 1 – this created the Item Framework

2 diabetes. The group of women who received pre-pregnancy care differed from those who did not, in several ways. Those who attended were slightly older (33.8 vs 31.9 y, P < .001), had a longer duration of diabetes (11.7 vs 9.5 y), had a lower HbA1c (7.4% vs 8.1%, P < .002), and a higher proportion had not experienced pregnancy previously (45.0% vs 38.9%, P< .001) (Egan et al., 2016).

A number of other studies support these findings and, in particular, suggest that women of older age and longer duration of type 1 diabetes possess more knowledge about the importance of preparation for pregnancy. However, the evidence is inconsistent and in some cases, conflicting, with one study reporting women with type 1 diabetes of longer duration, were *less* likely to attend pre-pregnancy counselling - adjusted odds ratio 1.16, 95% CI 1.09–1.23 per year increase for those with < 15 years' diabetes duration (Glinianaia, Tennant, Crowder, Nayar, & Bell, 2014). However, in this case, based on the majority of studies reporting longer duration of diabetes as a positive predictor, this was used as one of the predictors underpinning item generation.

As well as predictors, I considered relevant barriers - psychosocial reasons for non-attendance at pre-pregnancy counselling are reported to include previous negative experiences with diabetes healthcare professionals, feeling that the recommended glycaemic targets are unachievable, costs and other difficulties in attending clinics for low income families, unexpected pregnancies, and rapidly changing life situations (Murphy, 2010). Women in subsequent pregnancies may believe that they no longer need pre-pregnancy counselling and are, therefore, less likely to attend (Komiti et al., 2013; Komiti et al., 2014; Murphy et al., 2010b). Of particular relevance to Australia, an Australian study of rural and remote care concluded that women with type 1 diabetes in the rural setting experienced significant hardship during their pregnancy. These difficulties were compounded by both the

lack of available information to support the management of pregnancy, and experienced healthcare professionals (King & Wellard, 2009).

Finally, in relation to health care systems and access to pre-pregnancy counselling, despite the greater probability of women with longer duration of diabetes having experienced discussions about pregnancy, some may be unaware that specialised pre-pregnancy services exist, or may not be offered access to these (Lavender et al., 2010) (Egan, Carmody, Kirwan, & Dunne, 2017a; Murphy et al., 2010b; O'Higgins et al., 2014; Owens et al., 2016).

2. Development of structure & format for measure

After following all of these steps for item generation, including consideration of the predictors and barriers to pre-pregnancy counselling attendance, I developed a conceptual item framework. From here I presented a series of possible items for the Questionnaire pilot. After discussion within the research team, 41 discreet items were finalised from this initial item framework. After expert review, these were later reduced to the final 33 items for the pilot, consisting of two Likert scales, related to the construct of 'preparedness for pregnancy', as follows:

> SCALE 1 – Measuring knowledge of desirable health related behaviours for pregnancy in type 1 diabetes, and the importance placed on these; and
>
> SCALE 2 – Measuring the personal, social, and psychological resources the woman has available for the pregnancy journey.

Likert scales are one of the most common methods of measuring a scale. When these are used, it is usual to present a declarative statement, followed by the response items with varying degrees of agreement or endorsement of the statement. The response items need to be worded in a way that allows comparative intervals of agreement between them, and a neutral mid-point can be added (DeVellis, 2017).

Each item in the two scales of this Questionnaire is intended to be assessed individually, rather than resulting in a number rating. It is focused on facilitating discussion and planning. The Questionnaire is intended to be used in a narrative way. Based on this, after consideration of options for Likert scale response items, two different 5-point Likert scales were chosen to best reflect the intended constructs for measure. For scale 1 the aim is to quantify knowledge of desirable health behaviours, and the value placed on these items. Therefore, the response scale is "very important – not important". For the personal, social and psychological resources needed for the journey in scale 2, the aim is to understand whether, and how often, these resources are available to the woman. Therefore, a response scale of "all of the time - none of the time" was chosen.

3. Expert Review

Once the Questionnaire was at this point, an expert review was needed to assess the face and content validity of the items and assist with refinement, prior to the pilot. It is usual in tool development, to ask a group of people who are knowledgeable in the content area, to review the item pool. This can confirm or invalidate the definition of the construct being measured and can assist in refinement of items (DeVellis, 2017).

The process began with review by an expert panel, experienced in diabetes care. The panel included a diabetes psychologist, a representative from Diabetes Australia and the National Diabetes Services Scheme who manages their diabetes and pregnancy programme, and a diabetes counsellor with a background as an English Teacher, who is a person with type 2 diabetes and mother to a woman with type 1 diabetes. This provided a broad range of experience and knowledge across professionals and diabetes expertise. These experts were selected by approaching a number of people known to me, who are or who have worked, in diabetes care and research; as well as consumer representation.

The aim was to review the draft Questionnaire for relevance, clarity and conciseness. Initially, I did not constrain the survey items to type 1 diabetes, considering that it might be beneficial to examine both type 1 and type 2 diabetes. However, following the pilot, this was considered to be inappropriate and only women with type 1 diabetes were included in the analysis. This is explained in more detail later in this chapter.

I developed an online survey in Survey Gizmo, containing the pool of 41 items. The panel were then asked to respond individually online, to a series of questions about each item as follows:

- Was it easy to understand?
- Could it be worded differently?
- What was its relevance to the construct of Preparedness?
- Should it stay in the Questionnaire and why?
- How acceptable might the item be to women with diabetes and to health care professionals?
- Could they foresee any issues for women with diabetes in responding to each item?

These questions were intended to elicit whether the Questionnaire would support both the content and the process of communication.

4. Item Refinement

The expert panel review resulted in a reduction of the items from 41 to 30. Where all three experts individually reported that an item was not needed, it was removed. The language was changed on some items to be more positive and less judgemental. In particular, some repetitive items were removed, and the word “need” was changed in a number of cases.

Self-report scales rely on the assumption that each item elicits information only about the construct they aim to measure, but various response biases can be problematic. In particular, where there can be a power differential, such as in this case, response acquiescence can be an

important problem to manage (Primi, Santos, De Fruyt, & John, 2019). If a health care professional is providing the Questionnaire to a woman with type 1 diabetes, there is potential for responses that reflect what she thinks the health care professional would like to hear. In particular, this could be problematic on questions related to health behaviours. This was revealed in the cognitive interviews, as being of concern in the pilot and are reported on in the results. Following the expert review and input from the diabetes psychologist on my supervision team, I therefore added three additional items to the Questionnaire, that were not considered of high importance in the construct of preparedness for pregnancy, to help reduce response acquiescence bias, resulting in a final number of 33 items. The concept behind this was that high scores on those items could suggest response bias across the scale. We were aiming to see respondents answer these questions as being of less importance than some of the other items (see Appendix 2).

5. Pilot Testing and Analysis

Inclusion and Exclusion Criteria for the Pilot

I determined that in order to be included in the pilot, women had to have type 1 or type 2 diabetes; be aged 18 – 40; be able to speak English fluently; live in Australia; and be considering having a baby in the next 5 years. The aim was to use a sample of women who would be representative of those who might be most likely to be given the Questionnaire in practice. As stated, whilst my thesis is focused on type 1 diabetes, at this point I was considering that the Questionnaire might eventually be relevant to both type 1 and type 2 diabetes. As well, responses from women with type 1 and type 2 diabetes could have been compared and contrasted. However, we recruited mostly women with type 1 diabetes and so in the final analysis, type 2 diabetes was not included. In addition, while women over 40 might have had children, be currently pregnant or planning pregnancy still, it was decided that age 40 was an appropriate cut-off age given our focus on women contemplating

pregnancy at some time in the future. Gestational diabetes was excluded as issues pertaining to preparedness are irrelevant, given that diabetes does not exist prior to pregnancy. Furthermore, while a woman with gestational diabetes is at substantially higher risk of type 2 diabetes and gestational diabetes in subsequent pregnancies, it was considered that in the timeframe given, the scope would be too broad if gestational diabetes was included. Likewise, it would be beyond the scope of the study to include women who do not speak English.

Participant Recruitment

Recruitment for the pilot occurred between 28 February 2018 and 30 June 2018 via social media, email and health care professional networks (See Appendix 3). Contact was made via email to numerous diabetes organisations, as well as professional bodies. The most positive response came from postings on multiple Facebook pages, groups, email newsletters and websites/blogs. These included consumer groups, Diabetes Australia, the Australian Diabetes Educator's Association, National Association Diabetes Centres, the Australian Centre for Behavioural Research in Diabetes and the National Diabetes Services Scheme. Reach out via social media groups and diabetes blogs directly to people with diabetes proved to be the most effective mechanism in recruitment. After receiving information about the study, women were invited to contact the researcher for more information. The researcher then provided out the participant information sheet and consent forms via email (see Appendix 4). Once these were returned, participants were provided with the survey link to complete online.

Sample Size and Pilot Format

23 women were recruited during the pilot of the survey Questionnaire. 21 of these women had type 1 diabetes. 3 were interviewed via video, using cognitive interview techniques. The final 33 items were added to an online survey in SurveyGizmo. Along with the 33 items, questions about diabetes complications, HbA1c, medications and general health and diabetes

management, were included as pre-screener items. These are asked following the response to whether you are considering having a baby in the next 1-5 years. If the woman was not contemplating pregnancy during this time, she was instructed to not continue. The 33 questions then followed, with the 2 Likert Scale response items. The expected timeframe to complete the survey was predicted to be no more than 30 minutes. Privacy was protected with no identifying information being included.

Following the completion of the pilot survey, I undertook a 3-phase analysis to determine content and face validity, which included:

1. Cognitive interviews with 3 of the women;
2. Basic descriptive statistics; and
3. Scale Reliability Analysis.

I will now present the discussion and rationale for this approach to the pilot analysis, followed by the results.

QUESTIONNAIRE PILOT: COGNITIVE INTERVIEWS

Inclusion of consumers in the development of public health strategies and the development of decision-making tools is reported to enrich the process and outcomes, with questionnaires being the most commonly used tool for data collection (Farnik & Pierzchała, 2012). Questionnaires are regularly used to investigate many aspects of health, and while it may seem to be a straightforward process to develop such a tool, a large body of evidence has established that items researchers might themselves consider very clear, can be easily misinterpreted and may not measure what they intended (Willis & Artino, 2013).

One of the most important factors is to consider any issues related to the wording of the items, to ensure responses are as accurate as possible. More recently questionnaires have been assessed in a systematic way, using theoretical frameworks and methods derived from cognitive and social psychology (Haeger H, 2012). There is a growing body of literature to

suggest that the cognitive interview is an important method to measure the quality and accuracy of questionnaires. It can be used to identify and analyse any potential markers for response errors (Haeger H, 2012).

Cognitive interviewing has traditionally used a 4-stage cognitive model introduced by Tourangeau (Tourangeau, 1984) which describes the questionnaire response process as involving (1) comprehension, (2) retrieval of information, (3) judgment or estimation, and (4) selection of a response to the question. The potential for confusing questions can be minimised when developers use established survey design procedures (Willis & Artino, 2013). It is critical that questionnaires measure what is intended, and that respondents understand and interpret items correctly. Along with statistical analysis, the cognitive interview method is now seen as an important way to help evaluate the quality and accuracy of survey tools, and is used to identify and analyse potential for error (Heather Haeger, 2012).

The purpose of cognitive interviews is to focus on the actual questions themselves, rather than the person responding to them i.e., the researcher is primarily interested in the quality and relevance of the items. Cognitive interviews can be carried out either before data collection (pre-testing), during data collection, or after the questionnaire has been administered, as a quality assurance procedure (Willis & Artino, 2013). In this case, the cognitive interviews were carried out after women's completion of the pilot survey, to determine the quality and validity of the items from their perspective. This was followed by the basic psychometric testing.

Cognitive Interview Methods for Study 2

Following the online survey, all 21 participants with type 1 diabetes were invited to participate in the cognitive interviews, with three women responding positively. The other 18 women either did not respond, or were unable or not interested, in participating. Each interview was held via video and recorded, so the content could be transcribed later.

Cognitive debriefing is generally carried out as the "think aloud" method, or by using verbal probing techniques (Farnik & Pierzchała, 2012). In this study verbal probing was used following completion of the online pilot Questionnaire. This process is based on particular categories of cognitive probes, such as comprehension and interpretation; paraphrasing; and general probes, such as whether the respondent found the question to be difficult and whether the scale allowed them to answer in the way they would have wished. The questionnaire is then revised based on the results of cognitive debriefing (Farnik & Pierzchała, 2012).

The interviews carried out via video, therefore, consisted of asking the following for each item in the Questionnaire:

1) Did you understand the question? (state the question aloud) (intent, meaning of terms). If not, what was the issue with the question that made it hard to understand?

2) Do you have suggestions about how we could ask the question differently?

2) Retrieval of memory of relevant information to answer the questions - what type (s) of information did you need to recall and what types of strategies did you use to retrieve information needed to answer the question?

3) Decision processes – did you take time to answer accurately or did you choose to answer because you thought a given answer may be expected from you?

4) The response process - were the response options clear and allow you to choose the appropriate answers?

5) Do you have any general comments e.g., if the questionnaire is considered as being too long; any items that are not needed, or any new items that should be included – have we missed anything?

6) Do you think you could propose a better version of the questionnaire?

7) Any other comments?

Participant responses were transcribed, followed by collation in a table, describing the women's comments and recommendations for any changes to items. The summary table was used to present the results to the research team for discussion and was later evaluated in relation to the statistical analysis.

Interview Procedure

The interview commenced with explaining the purpose and process of the study to respondents. I stated that the purpose was to create a better version of the survey, rather than to assess their responses. Probes were systematically developed as above, before the interview, in order to search for potential problems (proactive probes) (Willis and Artino, 2013). The time taken to conduct the interviews was on average 40 minutes. The same order of questions was followed for each interview.

Treatment of Data

I conducted the interviews, working through each item in the Questionnaire with each participant. I transcribed the interviews from the video recordings as soon as possible after completion, in sufficient detail to review the interview and make appropriate conclusions. These data were then added to a table connecting the items and each of the three participant's responses. Because cognitive interviewing is a qualitative procedure, analysis does not rely on strict statistical analysis of numeric data, but rather on coding and interpretation of notes that are taken during or after the interview (Willis & Artino, 2013). Analysis usually considers a set of interviews, and combines notes relevant to each item, aggregating these across interviews, looking for common themes and identifying key findings that may indicate a need for item refinement. It is usual to have small numbers of participants (Willis and Artino, 2013).

In this case, the notes were summarised in a table (See Table 3), which included a summary of whether the participant felt the item was clear and easy to understand, or if there were

issues with an item. These were highlighted for further discussion within the research team. To enable deeper analysis, the table also included a summary of Cronbach's Alpha (carried out after cognitive interviews), which was determined in the scale reliability analysis. It was hypothesised that items which were not as internally reliable, might also exhibit difficulties during the cognitive interviews.

FREQUENCIES, CROSS-TABULATION AND SCALE RELIABILITY ANALYSIS METHODS FOR STUDY 2

Quantitative methods usually assess whether threats to internal validity and reliability have been managed. A survey questionnaire is thought to be valid and reliable when there is confidence that it measures what is intended (Sandelowski, 1986). This includes measuring what is being studied as defined within the study (content validity); whether it compares well with other tests measuring the same phenomenon (criterion-related validity); and that the results are congruent with the theory underlying the construct being studied (construct validity) (Sandelowski, 1986).

In this study options for testing validity and reliability were limited, due to the small number of respondents. Initially, frequencies were run on each item in SPSS, to ascertain the potential for further analysis. A table was drawn up, relating the relevant predictors described earlier, for attendance at pre-pregnancy counselling, with the items in the Questionnaire. This was to consider construct validity, measuring whether the results performed as would be predicted by current literature. This information was used for determining which item cross-tabulations to run. Cross-tabulations then provided information about the performance of each item in the Questionnaire, as compared to the predictors (see Table 2)

Cross Tabulation

The positive predictors to pre-pregnancy counselling identified in the literature were:

- Having type 1 diabetes – which was not relevant to this analysis, as all women included had type 1 diabetes.
- Age – older age correlates with higher likelihood of attendance at pre-pregnancy counselling.
- Duration of type 1 diabetes – longer duration is associated with greater likelihood of discussions with health care professionals around re-pregnancy counselling.
- Location – women are less likely to attend pre-pregnancy counselling or have had discussions about pregnancy, in a rural location.

Therefore, a series of cross-tabulations were carried out in SPSS including:

- Age+relevant scale items
- Duration of diabetes+relevant scale items. Duration was recoded into 3-time phases for analysis – 1-5 years, 6-15 years and 16 years+
- Rural location+relevant scale items

Items that had clustered responses on the Frequency tables were not included.

Cronbach's Alpha

Items that were negatively framed were reverse coded before performing scale reliability analysis. These were the items in the second scale, which related to worry, as the scale of very unimportant – very important, needed all responses to all flow in the same direction, prior to running Cronbach's Alpha. Scale reliability analysis was then carried out for each item, including the impact on Cronbach's Alpha should the individual item be deleted.

RESULTS

OVERVIEW OF PARTICIPANTS IN THE PILOT

Given the small number of women who might be considering pregnancy in Australia, as well as the small numbers of participants in comparative studies in the literature, 23 women (21 with type 1 diabetes) was considered a reasonable number of participants. However, this made full statistical analysis for validity and reliability challenging. Furthermore, with such small numbers it makes analysis based on the common predictors to pre-pregnancy counselling difficult, given only two of these women had previously been pregnant, and only two were in the 18-24- year-old age group, with two in the 35-44 year-old-age group. Women were also highly motivated, recruited via social media as shown in Table 2. It should be noted that as Latent Autoimmune Diabetes in Adults (LADA), is considered a form of type 1 diabetes, these women were included in the analyses. LADA is a form of type 1 diabetes where, despite the presence of islet antibodies at diagnosis, the progression of autoimmune β-cell failure is slow. People diagnosed with LADA do therefore not require insulin for at least the first 6 months after diagnosis (Stenström, Gottsäter, Bakhtadze, Berger, & Sundkvist, 2005).

TABLE 2 - Participant Information for the Contemplating Pregnancy in Diabetes Communication Support Questionnaire Pilot

Participant *(n=21)*	Type diabetes	Diagnosis	Age Range	Location & Postcode	HbA1c	Spoken to an HCP re pregnancy	Prior Pregnancy
1	1	1995	25 to 34	Urban 2500	7.200	Yes	No
2	1	2003	25 to 34	Rural 2076	7.300	Not applicable	No
3	LADA	2014	35 to 44	Urban 3072	6.000	Yes	Yes
4	1	2003	25 to 34	Urban 2165	7.500	Yes	No
5	1	2008	25 to 34	Urban 3095	7.100	No	No
6	1	2007	25 to 34	Urban 4000	7.200	Yes	No

7	1	2014	25 to 34	Rural 6153	6.900	No	No
8	1	2004	18 to 24	Urban 3021	8.500	No	No
9	LADA	2015	25 to 34	Rural 0810	6.500	Unsure	No
10	1	2016	25 to 34	Urban 6149	7.300	No	No
11	1	1997	25 to 34	Rural 2144	7.100	No	No
12	1	2001	25 to 34	Urban 2153		Yes	No
13	1	1997	25 to 34	Rural 3185	9.400	No	No
14	1	1998	25 to 34	Urban 2611	8.300	Unsure	
15	1	2012	25 to 34	Urban 4109	7.300	No	Yes
16	1	2012	25 to 34	Rural 2008	5.600	Yes	No
17	1	2008	25 to 34	Urban 3039	8.400	Yes	No
18	1	2007	18 to 24	Unsure 6065	7.000	No	No
19	1	2000	25 to 34	Urban 2155	8.300	No	No
20	1	1998	35 to 44	Urban 2135	6.700	No	No
21	1	1993	25 to 34	Sometimes Rural 3000	10.500	No	No

OVERVIEW OF PRE-SCREENER QUESTION ANALYSIS

The pre-screener questions were included in the Questionnaire based on the predictors of attendance at pre-pregnancy counselling suggested by the literature: including location, age, type of diabetes, duration of diabetes and previous pregnancy. Questions around women's prior contact with diabetes and pregnancy health care professionals and specialists and their beliefs about the importance of pre-pregnancy counselling, were also included.

The initial question, *"Do you think it is possible that you might be interested in having a child in the next 1 – 5 years?"* was based on the body of literature that suggests information about pregnancy provided at a time that is irrelevant to the woman, can have unintended consequences. It was agreed by the research team that placing a timeframe on this was

important. A timeframe of 1-5 years was selected, with the aim for the Questionnaire to be used at least once a year with individual women, in order to reach those who might not be considering a baby now, but might within the next 12 months. The recommendation is for the questionnaire to therefore be offered at least every 12 months.

The next item, *"Do you think pre-pregnancy planning and care is important for women with diabetes?"* was included to assess respondents' knowledge about the importance of pre-pregnancy counselling. This would also initiate the process of raising pre-pregnancy counselling as a topic of conversation, which would enable discussion with the health care professional, following completion of the Questionnaire.

As shown in chapter 1, given that women who have previously been pregnant are reported to have a lower attendance at pre-pregnancy counselling, the Questionnaire then asks a series of questions around pregnancy as follows, "*Have you ever been pregnant? If so, how many times?" Were any of your prior pregnancies planned? Have you had diabetes during any of your pregnancies? If so, how many times? Do you have any biological children? If so, how many? Have you ever had diabetes during the time you were planning a pregnancy?"*

Respondents are then asked a series of questions pertaining to their diabetes, to establish diabetes management, duration of diabetes, and experiences of complications. These are all relevant to the recommendations from ADIPS for pre-pregnancy counselling and a healthy pregnancy ("ADIPS Consensus Guidelines for the Testing and Diagnosis of Hyperglycaemia in Pregnancy in Australia and New Zealand | Australian Clinical Practice Guidelines," 2015).

"What type of diabetes do you have? When were you diagnosed with diabetes? Do you know your most recent HbA1c? If so, please select from the following (drop-down box options). Have you experienced hypoglycaemia (low blood glucose)? Do you monitor your blood glucose? If so, how are you monitoring it (e.g. finger pricks and/or continuous glucose monitoring). How often do you monitor your blood glucose each day? Do you know if you

have any of the following diabetes related complications? Please select all that apply (drop-down box). Are you having regular checks for the following diabetes complication? Please select all that apply (drop-down box). How are you currently managing your diabetes? Please select all that apply (drop-down box).”

Respondents are finally asked a series of questions about their household makeup, location and contact with a diabetes and pregnancy clinic. “*What is the make-up of your household? Do you live in a rural or regional area? Have you ever visited a diabetes and pregnancy clinic or specialist?”*

ANALYSIS OF SCALE 1 ITEMS – DESIRABLE HEALTH RELATED BEHAVIOURS FOR PREGNANCY AND DIABETES

The scale 1 items were developed based on the Australasian Diabetes in Pregnancy Society consensus guidelines for the management of type 1 and type 2 diabetes in relation to pregnancy and literature around predictors to pre-pregnancy counselling attendance relevant to type 1 diabetes. Before conception these recommendations include commencement of high-dose folate supplementation, review of medications including complementary medicines, and screening for diabetes complications. It is recommended that management should be by a multidisciplinary team experienced in the management of diabetes in pregnancy. The pre-conception review should include a reassessment of diabetes education, with the goal of ensuring adequate self-management skills, including sick day care and hypoglycaemic management, diet - including suggestions for dealing with morning sickness, and a physical activity regimen (McElduff et al., 2005).

The participants were asked to rate these items from very important – very unimportant, to enable assessment of both knowledge and the importance placed on each item. Two items – “*manage my diabetes with the latest technology available such as insulin pumps and continuous glucose monitors*” and “*have a fitness assessment at my local gym or health*

centre" – were added as items that were *not* considered important. This was to assist with the evaluation of credibility of responses. It is common to add negatively worded items that represent low levels, or an absence of the construct you are measuring (DeVellis, 2017). The aim was to include some items that show a high level of latent variable when selected and others, a high level when not selected. The goal is to reduce or avoid agreement bias – which is a potential problem for health care professionals administering this Questionnaire with women in their practice (DeVellis, 2017).

Scale 1

"We would like to understand what you know about the recommended steps in planning and managing pregnancy when you have diabetes, and how important these things are to you. If you were to get pregnant in the next 1-5 years, how important would the following actions be to you? Please indicate your response to the following as - Very Important, Important, Neither Important or Unimportant, Unimportant, Very Unimportant."

If and when I decide I want to have a baby, I will take the following actions before starting to plan my pregnancy:

1. Talk with my diabetes care team about what steps to take in preparing for pregnancy
2. Use contraception until I talk with my diabetes team about planning for pregnancy
3. Talk with my health care team about the target for my HbA1c before I start planning for pregnancy
4. Take high dose (5mg) folic acid prior to and during my early pregnancy [from and up to the time advised]
5. Stop or change any potentially harmful medications I may be taking before pregnancy, as recommended by my doctor
6. Manage my diabetes with the latest technology available such as insulin pumps and continuous glucose monitors

7. Have routine checks for diabetes complications such as retinopathy and kidney health
8. Have a fitness assessment at my local gym or health centre
9. Even if I have already had a baby, see my diabetes team for pre-pregnancy care
10. Reduce my alcohol consumption to the recommended safe drinking levels for women when planning a pregnancy, and to zero once pregnant
11. Work with my health care team to achieve healthy blood pressure levels
12. See my doctor for a review of all medications I am taking, including complementary medicines and supplements
13. Discuss a healthy exercise and eating plan with my diabetes team
14. Speak with my health care team about how I am feeling about my diabetes, and any concerns I have about how it may affect pregnancy.

ANALYSIS OF SCALE 2 ITEMS - THE PERSONAL, SOCIAL AND PSYCHOLOGICAL RESOURCES AVAILABLE FOR THE JOURNEY

The items in scale 2 were developed from the study one and the key issues presented in the literature around pregnancy and type 1 diabetes. The aim was to incorporate the themes developed during the item generation process, relating to the personal, social and psychological resources available to the woman for the journey. These were initially broken into 2 different response scales, but on the recommendation of the supervisory team, was confined to 1 scale, to reduce response burden. The response scale was determined to relate to a time-based measurement, in order to evaluate how *much* of a problem these items might be for the woman.

Scale 2

"Planning a pregnancy with diabetes requires a range of personal and social supports and resources. We would like to understand for you, what things might get in the way, and what things might make it possible, for you to have a healthy pregnancy and baby. Rate how often

the following statements apply to you (all of the time, some of the time, unsure, a little of the time, none of the time).”

If and when I decide I would like to have a baby, I think that:

1. Looking after my emotional wellbeing and mental health would be just as important as caring for my physical health
2. I would worry about changes to my diabetes management during pregnancy
3. I would worry about the impact the effort of managing diabetes during pregnancy would have on my loved ones
4. I would worry about the impact of my diabetes on my baby
5. It would be too demanding to achieve blood glucose levels within the target range before conceiving
6. It would be too demanding to maintain target diabetes management throughout pregnancy
7. I might not be able to continue my daily work or other activities when managing diabetes and pregnancy
8. I would be overwhelmed by all the things I need to do to plan and prepare for pregnancy
9. Being connected to other people with diabetes via social media and other websites would be helpful for my wellbeing
10. I would feel confident about managing diabetes during pregnancy
11. In general, I could be open with my health care team about any struggles I have with diabetes and not feel judged
12. The focus on my diabetes would make it hard to have a positive pregnancy experience
13. My family would be supportive of my desire to have a baby

14. My family may want to be too involved in my diabetes management during pregnancy
15. I already have a team of health care professionals who understand diabetes and pregnancy to support me when ready
16. I might feel isolated from people who understand what is needed in managing diabetes and planning a pregnancy
17. I would use diabetes related websites and social media groups for information and support about pregnancy and diabetes
18. I would use general pregnancy websites and resources for information and support
19. Being connected to other women with diabetes who have been through pregnancy would be important to me

COGNITIVE INTERVIEW OVERVIEW

Using proactive probing, respondents in the cognitive interviews revealed a number of difficulties with recalling or understanding information in relation to number-based responses in particular, such as hypoglycaemia, folic acid, and high blood pressure. It was recommended these items be better defined. Other items that caused concern were those related to health care professional involvement. The major problem for respondents associated with rating whether they had ever experienced hypoglycaemia, was the definition of what was meant by hypoglycaemia.

Responding to items such as reporting your last HbA1c, whether having a healthy blood pressure was important, and the need for high dose folic acid, were seen as potentially problematic by all respondents. One respondent said the pre-screener item about hypos was the most difficult one to recall – *"I always get a little bit confused when asked about hypos as I don't know if they mean just a low BGL before 4 mmol, or if I have experienced one where I needed to be hospitalised. I think I answered yes, as you have in brackets low blood glucose,*

so I went with the usual below 4 range I normally go with. I said yes and hoped it was what you were after. Might be good to define a number to guide which would make it easier to answer". With the HbA1c she also *"took a bit of a guess"* as her HbA1c is usually about the same but the exact result would only be fresh in her mind, if she had a recent appointment.

In relation to the hypo item, a second respondent said, *"this one, especially if a type 1, whenever a doctor asks me that I laugh a little! I have type 1 – a bit of a moot question but may be important for a type 2. Would be good to define what this means – e.g. below 3.4 (or a serious hypo question addition). If it was a serious hypo my answer would be no".* She felt the HbA1c item to be straightforward.

The third respondent said in relation to the hypo question, *"has that been defined as standard or extreme? Putting a definition of – have you experienced BGL below 3.5 etc – could make it into 2 questions – have had an extreme hypo below (e.g.)2 mmol or hyper in the past x months".* She felt the HbA1c item to be clear, but the one in relation to folic acid in scale 1, was more problematic – *"Made sense and I answered accurately but I was not aware of this before and did not know what folic acid is or what a high dose would be. This would mean it is not very important to me at this point in time. I answered in terms of what I knew, but if I knew what it was and what it did or how it might affect my diabetes I might have answered differently. Is it possible to have a small link to a website that explains what it is? Some sort of explanation that might help my answer be more accurate. Gaps in knowledge – why might women say it is not important?".*

Rating: *in general, I can be open with health care team and not feel judged* was the most problematic item for all three respondents. Their comments were consistent. One respondent said, *"some people I would feel more ok with than others talking about my worries with – there are so many people involved. If the person asking me the questions was someone, I did not feel comfy with, I would put all the answers in the middle".*

The second respondent said, *"potentially honesty in answer may be a big part. Whether people are going to be honest enough to say they are struggling or will say 'of course I will talk to them' because that is what a good diabetic is supposed to do".* Removing the word "judge" which could have negative responses, was seen as an important change.

The third respondent said, *"a good question and I put more thought into this question because number 1, my health care team involves a lot of people and for some people I would feel judged e.g. Endo, but then my diabetes educator I would not feel judged by her if I opened up. There are people I could open up to more than others. I put a lot of thought into this and there was a lot of confusion about how to answer it. However, you are asking in general and so I generalised it based on how many I feel comfortable with vs how many I don't feel comfortable sharing with. Was quite a thought process. Would depend on who was asking me to do the questionnaire – if doing it with the Endo and I knew he would talk with me afterwards I would answer differently, if someone who would not judge me, I would answer honestly, but if they would be judging me, I would be answering a few of these questions quite differently. Because I have had diabetes a long time and I am a woman I get the feeling from my Endo in particular that I should have more knowledge than I do have about diabetes and pregnancy. So yes, judgment of the person asking me to do the survey will change my answers. Very important question to have in there – important to know if women have someone in their team they can talk to if feeling burned out etc".*

Responding to: *the focus on my diabetes would make it hard to have a positive pregnancy experience* - concern was expressed by all three respondents in relation to the wording in this item. It was seen as containing jargon. One respondent commented, *"this has emotive language in it – wonder if someone is feeling bad about not having anyone available to support them and then they get to this question, how would they feel? I have been doing a lot*

of reading – there is no exact positive pregnancy experience – we are all different. Maybe it is around enjoying being a mum to be?"

A second respondent said *"this is clear, I don't necessarily know what a positive pregnancy experience is, can have a guess, but easy enough to follow. It is about how much it would affect my enjoyment of the pregnancy – the focus on diabetes might make it less possible for me to enjoy my pregnancy".*

The third respondent also had difficulty with interpretation of this item, saying, *"not sure how to answer it based on the wording. I find it hard to read the question. What is a positive pregnancy experience? What does that actually mean? It would be hard to enjoy pregnancy because the diabetes would take over?"*

Responding to: *I already have a team of health care professionals who understand diabetes and pregnancy to support me when ready* - as with the other items related to health care teams, this item was concerning to some respondents. One said, *"do you mean all or one of them? Some may get it and some don't – definitely wouldn't go to the GP, but they are the one who refers out so you want them to understand in a way. I have at least one HCP who understand diabetes and pregnancy to support me when ready and they can refer you when ready. My DE does that when I need advice about someone to see – 1 coordinating person".*

A second respondent said, *"this establishes whether they have a supportive HC team. Try and pinpoint where there are supports and positive and negative – 'already having' is a good way to ask. If sitting with an HCP however, they may feel pressured they have to say "all the time" and 'team' isn't associated with a diabetes clinic per se. Will depend on what environment the person is answering the questions in".*

The third respondent said, *"I have an idea about who I have available when I do want to plan pregnancy but if those conversations had not come up before, people might not have an idea about who they have available to them – also look at this the same as HC teams".*

The major problem with responding to the item *"have you visited a diabetes pregnancy clinic or specialist?"* was also the definition of this, suggesting some women may not know what a specialist pregnancy clinic is, or that they exist. The major problem with the item *"in general I can be open with health care team and not feel judged",* included concerns about the person administering the Questionnaire – in that if that was a health care professional who women did not trust to share their worries with, they might answer dishonestly. Further issues raised were in relation to the question about diabetes impacting on their chances of a *"positive pregnancy experience"* – respondents felt that it was too hard to know what a *"positive pregnancy experience"* would be.

SCALE RELIABILITY OVERVIEW

The scale reliability analysis showed a high level of internal consistency in the first half of the Questionnaire, related to desirable health related behaviours, with $\alpha = .9$ while the second half of the Questionnaire did not show such a high level, with $\alpha = .6$. This is likely to reflect the measurement of a number of constructs by scale 2.

Table 3- Cognitive Interview Analysis with Cronbach's Alpha if the Item were Deleted

Item	Participant 1	Participant 2	Participant 3	Alpha if deleted
PRE-SCREENERS	All questions made sense to me	Order of the questions in this section needs changing – ask what type diabetes at the top and the diagnosis question.	All questions make sense to me	NA
Do you think pre-pregnancy planning and care is important for women with diabetes?	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	NA
Have you ever been pregnant? If so, how many times?	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	NA

Were any of your prior pregnancies planned? Have you ever had diabetes during any of your pregnancies? If so, how many times?	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	NA
Do you have any biological children? If so, how many?	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	NA
What is your age?	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	NA
Have you ever had diabetes during the time you were planning a pregnancy?	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	NA
What type of diabetes do you have?	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	NA
When were you diagnosed with diabetes?	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	NA
Do you know your most recent HbA1c? If so, please select from the following (a dropdown box was included with HbA1c value ranges)	Clear and easy to understand	Clear and easy to understand	Most difficult to recall was HbA1c. I took a bit of a guess.	NA
Have you experienced hypoglycaemia (low blood glucose)?	Would be good to define what this means – e.g. below 3.4 (or add "a serious hypo ") I said yes, but if it was a serious hypo my answer would be no	Has that been defined as standard or extreme HYPO? Putting a definition of – have you experienced BGL below 3.5 etc – could make it into 2 questions – have had an extreme hypo below (e.g.) 2 mmol	I get confused when asked about hypos. I don't know if they mean - just a low BGL before 4 mmol? or experienced one where I needed to be hospitalised? Might be good to define a number to guide which	NA

			would make it easier to answer.	
Do you monitor your blood glucose? If so, how are you monitoring it (e.g. finger pricks or continuous glucose monitoring)	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	NA
How often do you monitor your blood glucose each day?	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	NA
Do you know if you have any of the following diabetes related complications? Please select all that apply	Clear and easy to understand	Maybe add do you have any other health conditions as well as diabetes? Comorbidities not just complications.	Clear and easy to understand	NA
Are you having regular checks for the following diabetes complications? Please select all that apply	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	NA
How are you currently managing your diabetes? Please select all that apply	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	NA
What is the make-up of your household? (Live at home with parents, live alone, live with friends, live with partner, other - please write in)	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	NA
Do you live in a rural or regional area?	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	NA
Have you ever visited a diabetes and pregnancy clinic or	Was fine because I do know they exist. If someone doesn't know	Fine – but do you need a time frame here? Might be better to ask –	I was a little bit unsure if you wanted to know if I had visited a	NA

specialist? (Yes, No, Unsure)	they exist they may say well have I done this? Need to say *"Have you ever spoken to an HCP about diabetes and pregnancy"* – more about whether someone has said anything or nothing.	*have you ever discussed pregnancy with any health care professional* –and potentially could put a time frame on it	diabetes and pregnancy clinic specifically? I have talked with my Endo and DE about pregnancy – wasn't sure if that sort of conversation counted for this question or not. Potentially an additional question – "*have you ever had any sort of conversation with your diabetes specialist or other HCP about diabetes and pregnancy?*"	
SCALE 1: Desirable Health Related Behaviours for the pregnancy journey. ***"If and when I decide I want to have a baby, I will take the following actions before starting to plan my pregnancy:"***	Easy enough to understand but a few questions did not fall into important-unimportant category as I had not considered it and did not know where I lie – I have no idea! So was not sure how to answer	Wondering if any there's benefit if the respondent could compare to what they think is important to what Dr thinks is important? but that could be judgemental	The Likert response scale made sense. No other way to ask off the top of my head. Was clear to me when I was doing it, is easier than if I had to type in words or a number rating scale. The opening statement is clear.	**Overall Scale Cronbach's Alpha = .89**
Talk with my diabetes care team about what steps to take in preparing for pregnancy	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	.89
Use contraception until I talk with my diabetes team about planning for pregnancy	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	.89
Talk with my health care team about the target	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	.89

for my HbA1c before I start planning for pregnancy				
Take high dose (5mg) folic acid prior to and during my early pregnancy [from and up to the time advised]	I marked as neither unimportant or important, as I was unsure about this one/unaware about it	I have been on this for a few years now with a script from Dr, there could be confusion for women but saying high dose and 5mg it clarifies this. Perhaps add a "*prescribed high dose of 5 mg"* rather than a generic over the counter dose – might alleviate some of that potential confusion	Made sense but I was not aware of this before and did not know what folic acid is or what a high dose would be – this would mean it is not very important to me at this point in time. I if I knew what it was and what it did, or how it might affect my diabetes I might have answered differently. Some sort of explanation that might help my answer be more accurate.	.89
Stop or change any potentially harmful medications I may be taking before pregnancy, as recommended by my doctor	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	.88
Manage my diabetes with the latest technology available such as insulin pumps and continuous glucose monitors	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	.89
Have routine checks for diabetes complications such as retinopathy and kidney health	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	.88
Have a fitness assessment at my	Clear and easy to understand	Clear question but will depend on the	Not sure it is linked to pregnancy? Is	.9

local gym or health centre		preconceived prejudice to diabetes as to how this is interpreted e.g. someone with type 2 saying it is all about the weight thing. I am lucky as I get this as part of my clinic. It will be up to the individual as to how they perceive fitness	clear but not sure if it would give me any info, I needed to plan a pregnancy. Answered honestly but not sure where it fits with pregnancy. When doing it I didn't pick up on that	
Even if I have already had a baby, see my diabetes team for pre-pregnancy care	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	.88
Reduce my alcohol consumption to the recommended safe drinking levels for women when planning a pregnancy, and to zero once pregnant	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	.89
Work with my health care team to achieve healthy blood pressure levels	Clear and easy to understand	Specify this number? If someone has not had much information adding a number will not make them feel bad if they don't know the answer about what a healthy BP is, as it is included	Not sure what the implications of having an unhealthy BP would be on pregnancy? Has not been raised as something I have had explained – so again it is one I don't have a lot of knowledge about so would have not said as being very important	.88
See my doctor for a review of all medications I am	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	.87

taking, including complementary medicines and supplements				
Discuss a healthy exercise and eating plan with my diabetes team	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	.88
Speak with my health care team about how I am feeling about my diabetes, and any concerns I have about how it may affect pregnancy	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	.89
SCALE 2: Personal, Social and Psychological Resources Needed for the Pregnancy Journey. ***"If and when I decide I would like to have a baby, I think that:"***	I think the response scale for this is reasonable	I think this is a reasonable way to answer the questions	I think this is a reasonable way to answer the questions	.56
Looking after my emotional wellbeing and mental health would be just as important as caring for my physical health	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	.60
I would worry about changes to my diabetes management during pregnancy	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	.55
I would worry about the impact the effort of managing diabetes during pregnancy would have on my loved ones	Clear and easy to understand	Maybe – *"I would be worried about how managing diabetes during pregnancy would impact my loved ones"* – as long as they have a	I have more insight than what others might have. I have knowledge about what pregnancy might entail, and that there is a lot of effort, but	.54

		support network of “loved ones” it will be fine**.**	some people might not know that there is a lot involved. Wonder if having more information is helpful?	
I would worry about the impact of my diabetes on my baby	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	.54
It would be too demanding to achieve blood glucose levels within the target range before conceiving	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	.55
It would be too demanding to maintain target diabetes management throughout pregnancy	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	.51
I might not be able to continue my daily work or other activities when managing diabetes and pregnancy	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	.53
I would be overwhelmed by all the things I need to do to plan and prepare for pregnancy	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	.49
Being connected to other people with diabetes via social media and other websites would be helpful for my wellbeing	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	.60
I would feel confident about managing diabetes during pregnancy	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	.51

In general, I could be open with my health care team about any struggles I have with diabetes and not feel judged	Some people in my team I might feel more ok with than others. So many people involved. If it was someone, I did not feel comfy with asking me the questions, I would put all the answers in the middle. Perhaps ask *"There is someone in my health care team who I would trust to talk about with any struggles I am having with my diabetes"*	Potentially honesty in answer may be a problem. Whether you associate it more with trusting the diabetes team and open up to them with any struggles you are having - *"There is somebody in my health care team that I would trust to go and talk with about struggles that I am having with my diabetes"* – this is a good way to reword it because it removes the word "judge" which could have negative responses. Especially if doing it with an HCP who does judge you	The health care team involves a lot of people and for some people I would feel judged but not for others. I put a lot of thought into this and there was a lot of confusion about how to answer it. I generalised it based on how many I feel comfortable with vs how many I don't feel comfortable sharing with. Was quite a thought process. Would depend on who was asking me to do the survey. If I thought they would be judging me I would be answering a few of these questions quite differently.	.54
The focus on my diabetes would make it hard to have a positive pregnancy experience	Not sure how to answer it based on the wording. I find it hard to read the question – What is a positive pregnancy experience? What does that actually mean? It would be hard to enjoy pregnancy because the diabetes would take over? Needs change of wording – e.g. *I would worry that my diabetes would impact on*	This has emotive language in it – I wonder if someone is feeling bad about not having anyone available to support them and then they get to this question, how would they feel? I have been doing a lot of reading – there is no exact positive pregnancy experience – we are all different. *Maybe it is around enjoying*	This is clear, I don't necessarily know what a positive pregnancy experience is, can have a guess, but easy enough to follow – about how much it would affect my enjoyment of the pregnancy – how much you enjoyed the pregnancy – the focus on diabetes might make it less possible for me to enjoy my pregnancy	.53

	my pregnancy experience	*being a mum to be?*		
My family would be supportive of my desire to have a baby	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	.53
My family may want to be too involved in my diabetes management during pregnancy	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	.61
I already have a team of health care professionals who understand diabetes and pregnancy to support me when ready	Is the focus on all or one of them? Some may get it and some don't – definitely wouldn't go to the GP but they are the one who refers out so you want them to understand in a way – *"I have at least one HCP who understand diabetes and pregnancy to support me when ready"* may be best way to ask – they can refer you when ready. My DE does that when I need advice about someone to see – 1 coordinating person	If sitting with an HCP they may feel pressured they have to say "all the time" – "team" isn't associated with a diabetes clinic per se. Will depend on what environment the person is answering the questions in.	I have an idea about who I have available when I do want to plan pregnancy but if those conversations had not come up before people might not have an idea about who they have available to them – also look at this the same as HC teams	.52
I might feel isolated from people who understand what is needed in managing diabetes and planning a pregnancy	Question is a bit segmented – have to think about lots of different parts to bring it together – Maybe - *there might not be anyone else who understand* or *I*	Clear and easy to understand	Is it asking whether you would feel isolated from those people you do have available to you? Or that you feel isolated because you don't have	.58

	feel that I would not know any others who understand diabetes and pregnancy		people around you? A bit unclear – I made sense of it by feeling isolated from people - having no one available that understands what I am going through *maybe ask "I would worry that I don't have anyone around me who understands what is involved in managing diabetes and pregnancy"*	
I would use diabetes related websites and social media groups for information and support about pregnancy and diabetes	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	.51
I would use general pregnancy websites and resources for information and support	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	.57
Being connected to other women with diabetes who have been through pregnancy would be important to me	Clear and easy to understand	Clear and easy to understand	Clear and easy to understand	.55

[2]

[2] *The 3 participants were taken from the original group of respondents to the pilot survey (n=23). All women were invited. We are unable to identify which survey participants these were, due to the anonymity of the survey to protect privacy*

FREQUENCIES AND CROSS-TABULATION ANALYSIS OVERVIEW

TABLE 4 Results: Cross-Tabulation of relevant Items in Scale 1

Items in scale 1 with the response of very unimportant – very important, were correlated using cross-tabulation, against the three predictors in the literature of duration of diabetes, rural location and age. This was part of the process related to construct validity and was related to understanding what kinds of things might prevent or enable women to attend pre-pregnancy counselling, thus allowing me to determine whether scale items would perform as expected in the pilot – for example, whether being of older age correlated with being more likely to attend pre-pregnancy counselling in the pilot. This guided the next stage of reliability testing. A number of responses to items from the first scale in the pilot were not included in this cross-tabulation, because there were high numbers of clustered responses by participants. I was advised by the statistician supporting the project, that this would skew the correlation results and it was better to use items where there was a diversity of responses for cross-tabulation. The relevant items that were included therefore, are presented here in detail.

Table 4: Cross Tabulation – Item responses as rated against Predictors for Attendance at Pre-pregnancy Counselling (N=21)

SCALE 1: Desirable Health Related Behaviours for the Pregnancy Journey. ITEMS WHERE CROSSTABS WERE CARRIED OUT – rating very unimportant – very important	Predictor: Age	Predictor: Rural Location	Predictor: Duration of diabetes
Have you ever visited with a diabetes and pregnancy clinic or specialist?	+	+	+
Use contraception until I talk with my diabetes team about planning for pregnancy	X	+	+
Even if I have already had a baby, see my diabetes team for pre-pregnancy care	X	X	X
SCALE 2: Personal, Social and Psychological Resources	Predictor: Age	Predictor: Rural Location	Predictor: Duration of diabetes

Available for the Pregnancy Journey. ITEMS WHERE CROSSTABS WERE CARRIED OUT – rating none of the time – to all of the time			
Looking after my emotional wellbeing and mental health would be just as important as caring for my physical health	X	+	X
I would worry about changes to my diabetes management during pregnancy	+	X	+
I would worry about the impact of my diabetes on my baby	+	+	+
It would be too demanding to achieve blood glucose levels within the target range before conceiving	+	X	+
It would be too demanding to maintain target diabetes management throughout pregnancy	+	X	+
I might not be able to continue my daily work or other activities when managing diabetes and pregnancy	+	X	+
I would be overwhelmed by all the things I need to do to plan and prepare for pregnancy who have been through pregnancy	+	X	+
I would feel confident about managing diabetes during pregnancy	+	X	X
In general, I could be open with my health care team about any struggles I have with diabetes and not feel judged	+	X	+
The focus on my diabetes would make it hard to have a positive pregnancy experience	+	X	+
I already have a team of health care professionals who understand diabetes and pregnancy to support me when ready	+	X	+

3

[3] X = responses to item were not as predicted; + = responses to items were as predicted

- *Have you ever visited with a diabetes and pregnancy clinic or specialist?*

This result was as predicted, with older women more likely to have spoken with a health care professional about diabetes and pregnancy. Two women in the survey aged 18-24 years had not spoken with an HCP about pregnancy.

- *Use contraception until I talk with my diabetes team about planning for pregnancy*

In this item, which relates to knowledge, age did not score as predicted on cross-tabulation, with younger women more likely to have scored this as important. Rural location and length of time with diabetes were scored as predicted, with those in rural locations rating this as less important and those with longer duration of diabetes, scoring this as more important. However, it cannot be assumed where this knowledge has been gained from.

- *Even if I have already had a baby, see my diabetes team for pre-pregnancy care*

Bearing in mind these are very small numbers, in relation this item, it was predicted that older women would be more likely to rate this as important and those in rural locations might be less likely. However, this was not the case, with all age groups rating this as important or very important. 100% of women in a rural area also ranked this as important or very important, again indicating good knowledge.

TABLE 4 Results: Cross-Tabulation of relevant Items in Scale 2

Items in scale 2 with the response of none of the time – all of the time, were correlated using cross-tabulation, again using the three predictors in the literature of duration of diabetes, rural location and age. This scale measures across a number of themes related to social, personal and psychological resources. I was looking for not just ratings of importance, but how much of the time women thought these items might be issues for them, and therefore, where there might be flags for intervention. It was harder to correlate these items with the predictors because in some cases, such as mental health, all women might find this important. Therefore, it might seem from a purely statistical point, that this is an item that is

likely to not provide much information. However, in this case, as the tool is aimed at starting conversation, those items where all or most women found great importance for much of the time, it might in fact be a very relevant item. This is just as important therefore, as the results of Cronbach's Alpha. A number of items were included in cross-tabulations as follows.

- *Looking after my emotional wellbeing and mental health would be just as important as caring for my physical health*

Across all three of the age groups, women found this to be important all, or some, of the time. 100% of women across rural and non-rural locations found this important all of the time or some of the time; 100% of women of any duration of diabetes found this important all, or some, of the time. This suggests this item is of high relevance to women with type 1 diabetes and the question might offer an opportunity for health care professionals to discuss emotional and mental health in consultations.

- *I would worry about changes to my diabetes management during pregnancy*

This item correlated well with predictors for age, with 100% of younger women reporting they would worry about this all the time; 52.9% of women 25-34 years and 50% of women 35 years and over. Whilst small numbers, this might indicate that older women were more confident in their ability to manage diabetes during pregnancy. Rural location was not as strongly correlated, with fairly even responses across urban and rural location. Women who had diabetes for longer, appeared to worry more about changes to their management, which would be expected. 25% of the women diagnosed 1-5 years reported they would worry all the time, with 75% all the time. In the group diagnosed 6-16 years 66.7% would worry all the time; and in the 16 years+ 57.1% all the time.

- *I would worry about the impact of my diabetes on my baby*

Responses to this item were as predicted with 100% of women aged 18-24 years reporting they would worry about the impact of pregnancy on their baby all the time. 25 – 34 years old

was similar at 95.1% all the time; and the older age group of 35 years+ was 50% all the time. Again, this indicates that older women might feel more confident in their ability to have a healthy pregnancy. In rural or regional areas, the results were similar, with around 90% of women worrying all the time. In length of time with diabetes, most women worried about this no matter how long they had lived with diabetes, but the 1-5 years age group had a slightly lower percentage reporting all the time.

- *It would be too demanding to achieve blood glucose levels within the target range before conceiving*

In regards to this item, for age and length of time, the responses were quite varied, again showing older women possessing more confidence in their ability to manage diabetes prior to pregnancy. 100% of the younger women reported this would be true all the time. 76% of women 25-34 years reported all, or some, of the time; and 50% of women over 35 years, reported all the time. In relation to location, results were similar whether rural or urban location. In length of time 75% of women diagnosed 1-5 years reported they would be concerned about this just some of the time and 25% none of the time; compared to 37.5% of women who had been diagnosed more than 16 years worrying about this all the time, 37.5% some of the time, 12.5% unsure and 12.5% a little of the time. Women diagnosed 6 – 16 years reported 11.1% all the time and 66.7% some of the time.

- *It would be too demanding to maintain target diabetes management throughout pregnancy*

Responses to this item were as predicted across age and length of time. 50% of women 18-24 would worry about changes during pregnancy all the time and 50% some of the time. None of the women 35+ would worry about this all the time, with 50% worrying some of the time and 50% a little of the time. Women in the middle age group of 25 – 34 reported 23.5% all the time and 41.2% some of the time. In location the results were similar for urban or rural

location. Most women with longer duration of diabetes had concerns, with 75% diagnosed more than 16 years, reporting this would be a concern all, or some, of the time. Women diagnosed 6-16 years also reported 77.7% all, or some, of the time. Women diagnosed 1-5 years however, reported 25% some of the time, 50% were unsure. This might indicate that women with shorter duration of diabetes had less experience in management of diabetes, less awareness of potential issues, or lower rates of complications and diabetes burn out. But this is just a postulation.

- *I might not be able to continue my daily work or other activities when managing diabetes and pregnancy*

In relation to responses to this item, the responses were quite varied. 50% of women 18-24 would worry about this some of the time but 50% were unsure. 5.9% of women aged 25 – 34 reported they would worry all the time, 35.5% some of the time, 35% were unsure, with 25% saying a little of the time. 50% of women aged 35+ reported they would worry some of the time and 50% a little of the time. In relation to location, 30% of women in cities would worry all, or some, of the time, about this, while 50% of women in a rural location would worry some of the time. Around 35% of women in both rural and urban locations were unsure. 75% of women having diabetes 16 years+ reported they would worry about this all, or some, of the time, compared to 25% of women diagnosed 1-5 years worrying about this some of the time; 50% unsure and 25% a little of the time.

- *I would be overwhelmed by all the things I need to do to plan and prepare for pregnancy*

In regards age, most of the women said they would worry all, or some, of the time. 100% of younger women 18-24 years, said they would worry about this some of the time. 76% of women 25 -34 years, would worry all, or some, of the time. 50% of women 35 years+ reported some of the time and 50% a little of the time. This indicates the older women may

have again felt a little more confident in their ability to manage the planning period of pregnancy. Rural location was not as expected, with results being fairly even between rural and urban location. Duration of diabetes was as expected with 87% of women living with diabetes more than 16 years and 89% of women diagnosed 6-16 years worrying about this all, or some, of the time, compared to 50% of women diagnosed 1-5 years worrying some of the time and 50% a little of the time. It would suggest again that women with longer duration of diabetes might have more concerns about managing preparation for pregnancy.

- *I would feel confident about managing diabetes during pregnancy*

In relation to age, the results were as expected, but not for duration of diabetes or location. 50% of women 18-24 years would feel confident some of the time, 50% were unsure. Similarly, 41% of women aged 25 – 34 years reported they would also feel confident some of the time, 35.3% were unsure, 17.6% a little of the time and 5.9% none of the time. 100% of women aged 35years+ said they would feel confident some of the time. In relation to location, the results were very even no matter where the woman was located. 75% of women who had been diagnosed 1-5 years reported they would feel confident some of the time compared to 44.6% 6-15 years and 33% over 16 years. Around 30% of all age groups were unsure. 12.5% of women diagnosed more than 16 years felt they would feel confident none of the time.

- *In general, I could be open with my health care team about any struggles I have with diabetes and not feel judged*

This item performed as predicted for age and length of time with diabetes, but not location. 50% of Women aged 18 – 24 years reported they would agree with this statement all the time, 50% were unsure. 58.8% of women 25-34 years reported they would agree with this all, or some, of the time. 100% of Women over 35 years of age reported some of the time. 76% of women in rural locations agreed with this statement all the time, compared to just 23% in

urban locations, however 46.2% of women in urban locations reported some of the time. This item was suggested during cognitive interviews, as requiring re-wording, which is discussed below. In relation to duration of diabetes, women who had lived with diabetes for longer, reported they agreed less with this statement, suggesting they may have had interactions with health care professionals about diabetes and pregnancy in the past that had been negative. 100% of women living with diabetes 1-5 years said they could agree with this statement all or some of the time, compared to just 25% of women diagnosed more than 16 years. 77.7% of those diagnosed 6-16 years reported all or some of the time.

- *The focus on my diabetes would make it hard to have a positive pregnancy experience*

100% of women 18-24 felt this would be true all the time. 46% of women aged 25-34 years agreed with this statement all, or some, of the time, and 100% of women aged 35+ some of the time. This is opposite to the questions about diabetes management during preparation for pregnancy, where older women appeared to have more concerns. In this item, younger women seemed more concerned about the impact of diabetes on their pregnancy experience. 62% of women in an urban location reported this to be true all, or some, of the time, whereas rural location reported 33.3% some of the time.

- *I already have a team of health care professionals who understand diabetes and pregnancy to support me when ready*

50% of women 18-24 years reported this was the case all, or some, of the time. 65% of women aged 25-34 years reported this was the case all, or some, of the time. 100% of women over 35 agreed this was the case all the time, indicating a positive relationship with their health care team. In location, 83.3% of women in rural locations reported they have a health care team available all the time, whereas in urban locations they reported this as 7.7% all the time and 61.5% some of the time. This is not as predicted, with an expectation that urban

locations might have less health care professionals available. For duration of diabetes, the responses were relatively even across all time periods, with 75% of women diagnosed 1-5 years reporting all, or some, of the time; 66.6% of women 6-15 years reporting all, or some, of the time; and 62.5% women diagnosed more than 16 years reporting all, or some, of the time.

CRONBACH'S ALPHA RESULTS

TABLE 5: Cronbach's Alpha Results for Scale Reliability

Item	Mean	SD	Alpha if deleted
Scale 1- Desirable Health Related Behaviours for the Pregnancy Journey: Cronbach's Alpha = .89			
Talk with my diabetes care team about what steps to take in preparing for pregnancy	1.2	.4	.89
Use contraception until I talk with my diabetes team about planning for pregnancy	1.8	.9	.89
Talk with my health care team about the target for my HbA1c before I start planning for pregnancy	1.4	.6	.88
Take high dose (5mg) folic acid prior to and during my early pregnancy [from and up to the time advised]	1.6	.7	.89
Stop or change any potentially harmful medications I may be taking before pregnancy, as recommended by my doctor	1.4	.7	.88
Manage my diabetes with the latest technology available such as insulin pumps and continuous glucose monitors	1.5	.6	.89
Have routine checks for diabetes complications such as retinopathy and kidney health	1.7	.8	.88

Have a fitness assessment at my local gym or health centre	3.0	1.1	.90
Even if I have already had a baby, see my diabetes team for pre-pregnancy care	1.8	.6	.88
Reduce my alcohol consumption to the recommended safe drinking levels for women when planning a pregnancy, and to zero once pregnant	1.2	.5	.89
Work with my health care team to achieve healthy blood pressure levels	1.6	.6	.88
See my doctor for a review of all medications I am taking, including complementary medicines and supplements	1.8	.9	.87
Discuss a healthy exercise and eating plan with my diabetes team	2.1	.9	.88
Speak with my health care team about how I am feeling about my diabetes, and any concerns I have about how it may affect pregnancy	1.3	.5	.89
Scale 2: Personal, Social & Psychological Resources Available for the Pregnancy Journey Cronbach's Alpha = .56			
Looking after my emotional wellbeing and mental health would be just as important as caring for my physical health	1.3	.5	.60
I would worry about changes to my diabetes management during pregnancy	4.4	.7	.55
I would worry about the impact the effort of managing diabetes during	4.9	.3	.54

pregnancy would have on my loved ones			
I would worry about the impact of my diabetes on my baby	4.9	.3	.54
It would be too demanding to achieve blood glucose levels within the target range before conceiving	3.6	1.2	.55
It would be too demanding to maintain target diabetes management throughout pregnancy	3.6	1.1	.51
I might not be able to continue my daily work or other activities when managing diabetes and pregnancy	3.2	.9	.53
I would be overwhelmed by all the things I need to do to plan and prepare for pregnancy	3.6	.8	.49
Being connected to other people with diabetes via social media and other websites would be helpful for my wellbeing	2.1	1.0	.60
I would feel confident about managing diabetes during pregnancy	2.7	.9	.51
In general, I could be open with my health care team about any struggles I have with diabetes and not feel judged	2.2	1.2	.54
The focus on my diabetes would make it hard to have a positive pregnancy experience	3.4	1.0	.53
My family would be supportive of my desire to have a baby	1.2	.4	.53
My family may want to be too involved in my diabetes management during pregnancy	3.1	1.3	.61
I already have a team of health care professionals who understand diabetes and pregnancy to support me when ready	2.3	1.3	.52

I might feel isolated from people who understand what is needed in managing diabetes and planning a pregnancy	3.6	1.0	.58
I would use diabetes related websites and social media groups for information and support about pregnancy and diabetes	2.0	1.0	.51
I would use general pregnancy websites and resources for information and support	2.3	1.1	.57
Being connected to other women with diabetes who have been through pregnancy would be important to me	1.9	.7	.55

[4]

In the statistical analysis, overall, the first scale returned a Cronbach's Alpha = .9 showing high internal consistency. Removal of individual items made only slight differences to this, with the item in relation to fitness centres reaching the highest Alpha of .9 if removed. This may change in a larger number of women, particularly if type 2 diabetes was included. The second scale did not show high internal consistency, with a Cronbach's Alpha = .6 This could be because the scale considers a number of concepts – psychological wellbeing; family and peer support; and health care support. There were a number of items in this scale suggested as needing re-wording in the cognitive interviews.

[4] Scale 1 Mean Range = 1-5; 1= Very Important, 2= Important, 3 =Neither Important or Unimportant, 4= Unimportant, 5= Very Unimportant.

Scale 2 Mean Range = 1-5; 1= All of the time, 2= Some of the time, 3 = Unsure, 4 = A little of the time, 5=None of the time (negative items were reverse coded for scale reliability analysis)

[4] *N=21*

DISCUSSION

OVERVIEW

I have shown in this chapter that the use of questionnaires and survey tools in diabetes care, is common and useful, for many reasons. The literature review establishes that there are a number of survey tools which are commonly used in diabetes care. However, none of them addresses preparedness for pregnancy in type 1 diabetes, nor is aimed at supporting the process and content of conversations around this. According to the literature review, a tool that measures such a construct specifically, is likely to be more useful than a general survey tool, measuring wellbeing, for example.

This Questionnaire was developed to address the evidence presented here, showing:

1. that adverse outcomes of pregnancy persist for women with type 1 diabetes;
2. that pre-pregnancy counselling can reduce these risks;
3. that on average, less than 30% of women with type 1 diabetes attend pre-pregnancy counselling;
4. that women with type 1 diabetes may not be aware such services exist, or they may not be offered access to these; and
5. that relevant, balanced and timely communication about pregnancy between women with type 1 diabetes and their health care professionals, needs to be supported.

My research showed that a questionnaire might be a valuable way to address these issues, because it can be tested, standardised, and delivered in a variety of ways. Whilst full reliability testing was not able to be performed during this PhD, due to time constraints, the prototype Questionnaire, having now undergone preliminary testing, is ready for further work. I recommend that this included testing in larger groups of women with type 1 diabetes and that this is compared across a range of different health settings, including GP clinics,

diabetes clinics and pregnancy clinics. I also recommend that a pilot needs to be developed for use in women with type 2 diabetes, as compared to women with type 1 diabetes.

Despite being preliminary testing, this work still makes a substantial contribution to the body of work in relation to type 1 diabetes and pregnancy, because it highlights the importance of shared-decision making, person-centred care and improved communication between health care professionals and women with type 1 diabetes about pregnancy planning. It further offers the basis for a potential tool to both direct the content of such conversations and the encourages a positive process which is led by the woman with type 1 diabetes.

METHODOLOGICAL STRENGTHS AND LIMITATIONS

There are a number of strengths and limitations in this study. Firstly, the sample of women is small (N=21) and, accordingly, reliability cannot be fully ascertained from these results. Only two of the women had experienced more than one pregnancy; and only two were in the 18-24- year-old age group, with two in the 35-44 year-old-age group. The women were highly motivated, being recruited via social media. The methodology used in the analysis was, however, relevant to a small sample, and was supported by descriptive and qualitative methods, to determine face and content validity. The analysis is mostly descriptive. A larger sample would allow further reliability testing. While it is usual for cognitive interviews to include small numbers of participants, these findings are more suggestive than conclusive, and should be interpreted circumspectly.

SUMMARY AND IMPLICATIONS OF THE RESULTS

In summary, overall, the first scale in the Questionnaire performed well in the statistical analysis, with an average Cronbach's Alpha = .9 meaning high internal consistency, while the second scale did not show high internal consistency, with an average Cronbach's Alpha = .6. As previously suggested, this is likely to be because the scale considers a number of concepts – psychological wellbeing, family and peer support, and health care support. The

Questionnaire was overall acceptable to the three women who participated in the cognitive interviews, the questions made sense, and it was felt to be useful by the women. During the cognitive interviews, the length of the Questionnaire was seen as appropriate. Questions where women suggested specification of numbers – e.g. HbA1c, hypos and hypers – were expected to be easier to progress once this change is made. One woman reported she felt others would be open to doing the survey – *"it makes them aware that PPC is a thing and is available rather than all the negative info – we understand what you are about to experience, it is not scary and we are here to support you."* Overall the Questionnaire was seen as reasonably easy to complete; with a few items requiring more recall memory, *"Didn't take me too long to do it and nothing was really missed out".*

The item *"I would worry about the impact the effort of managing diabetes during pregnancy would have on my loved ones",* was seen as needing clarification by two of the women, with some suggestions of wording changes. The item *"In general, I could be open with my health care team about any struggles I have with diabetes and not feel judged",* was of concern for all three women. It was felt that there are many people in a team, and that if the person offering you the survey Questionnaire was someone you didn't trust, you would be less likely to answer honestly. Re-wording the item to *"There is somebody in my health care team that I would trust to go and talk with about struggles that I am having with my diabetes"* was suggested. The item *"The focus on my diabetes would make it hard to have a positive pregnancy experience"* was also recommended to have a change in wording. All three women felt that the idea of a "positive pregnancy experience" would be hard to define. It was suggested that a better way to ask this question might be, *"I would worry that my diabetes would impact on my pregnancy experience"*. The item "*I already have a team of health care professionals who understand diabetes and pregnancy to support me when ready"* caused some concern in regards to what a health care team is defined *as,* and again,

the pressure of responding in a certain way, depending on who is asking the questions. It was suggested the wording could be, *"I have at least one HCP who understand diabetes and pregnancy to support me when ready".* The item around feeling isolated was seen as confusing by two of the women. Suggested re-wording was *"I would worry that I don't have anyone around me who understands what is involved in managing diabetes and pregnancy".*

One woman suggested that with scale 2, the response item being time-based made her feel somewhat overwhelmed – e.g. "worrying about changes to my diabetes". This could lead to wondering, "*Should* I be worrying about this all the time? How often should I be worried?" and that, "If women already have a fragile mental state you don't want to suggest to them that they be worried all the time?". It was suggested potentially these worry items could be separated and a scale of – How much does this worry you? - with response items 1-10, be used. Another woman felt that there was nothing missed. However, her husband comes to clinic too, so he can also get the knowledge, know what to expect, what needs to be done and to secure an increased level of accountability. It was suggested a question asking whether the woman has a support network that assists them with their medical appointments – someone actively involved in the accountability - could be added, for example, *"There is someone in my life who could come to my appointments with me and support me in planning a pregnancy".*

This item about whether the respondent felt pre-pregnancy counselling was important or not, was seen by the researchers and the expert panel as vital to the Questionnaire, because it gets to the core of preparedness for pregnancy. It was a seemingly straightforward question. However, one respondent to the cognitive interviews thought that whilst straightforward, and that she would hope people would answer honestly, they may experience some guilt if they had not considered it before and/or if they have had adverse outcomes in prior pregnancy after not attending pre-pregnancy counselling. Another respondent suggested that perhaps

this particular item should be moved to the first scale, rather than the pre-screener items, so that it could be rated as very important – very unimportant and that this may minimise the potential for inducing guilt. Or, "How important or unimportant do you think pre-pregnancy planning might be in helping a woman with type1 diabetes to have a safe and healthy pregnancy?".

Guilt has been reported as an issue in the qualitative research relating to pregnancy and type 1 diabetes. How a woman will respond to the challenges of pregnancy depends on their identity, attitude, and available resources, including health professionals and social environment. Health professionals have a responsibility to not only assist the woman to have a healthy child, but to also support her to master the pregnancy, increasing self-efficacy, self-esteem and wellbeing into motherhood (Berg, 2005). Women might worry about jeopardizing their baby's health and this can be exacerbated by the manner of health care providers' and any lack of competence and support (Berg & Sparud-Lundin, 2009). In my first study, guilt was a common theme, with women's experiences being impacted by past experiences of pregnancy and the way information was provided – '*I have been so stressed and racked with guilt whenever I have higher levels, and it has only been 3 weeks – I will be a nervous wreck by the end of the pregnancy!!!!'* (Edwards et al., 2016). Moving this item to the first scale could assist with minimising this potential issue.

This Questionnaire was developed using well-known methodology for survey development. It was based on guidelines about pregnancy management in type 1 diabetes in Australia, evidence from study one, and the literature review. Whilst small, the analysis of this prototype Questionnaire has shown that with further testing, it has potential to provide busy health care professionals with an easier way to initiate discussions about pregnancy preparation, and the importance of pre-pregnancy counselling. It also provides the opportunity to raise pregnancy and type 1 diabetes at an earlier time than when planning

pregnancy – during Contemplation, a period which might last for many years. It aims to facilitate shared-decision making and the assessment of both knowledge and personal, social and psychological resources available to the woman for the pregnancy journey.

NEXT STEPS BEFORE IMPLEMENTATION

This Questionnaire is unique, and overall performed well in this small analysis for face and content validity. It potentially represents a positive addition to pregnancy and health care services for women with type 1 diabetes and indeed, with further testing and refinement, for women with type 2 diabetes. In practice, once fully tested for reliability, I foresee the Questionnaire being most useful if available via a number of options, including a website for download or completion online and via a mobile app. This would enable health care professionals to use the Questionnaire with women at regular appointments, either in waiting rooms or in the consult. Women could also access this online themselves and bring the results to an appointment. It should be recognised that this is a hypothesis generating study only, due to the limitations.

From my perspective, I propose the Questionnaire now needs to be modified as suggested during the analysis. Whilst the Questionnaire could then be used to begin conversations about preparedness for pregnancy with women with type 1 diabetes, testing in a larger group of women and/or further rounds of pilot testing and cognitive interviews with the refined survey, would provide further validation of internal reliability before use in practice. Therefore, before being widely administered, the Questionnaire requires testing in a larger and more diverse population of women with both type 1 and type 2 diabetes, which was not possible in the time constraints of the PhD. This should also include women from a variety of ethnic backgrounds, and given the international studies discussed in this thesis, could also be tested in other countries, to ascertain its applicability.

CHAPTER 5: USING INTERNET-BASED PROGRAMMES AND RESOURCES TO SUPPORT WOMEN WITH TYPE 1 DIABETES DURING THE PREGNANCY JOURNEY: A META-SYNTHESIS OF QUALITATIVE EVIDENCE

PREAMBLE

In study one, I developed a model of the pregnancy journey for women with type 1 diabetes, arguing that it is distinct from women without type 1 diabetes. The factors that make it distinct, include the increased importance of preparation for pregnancy, the recommendations for pre-pregnancy counselling, and the intensive nature of medical intervention across the pregnancy journey. I have suggested, based on this work, that women with type 1 diabetes experience diabetes-specific distress differently during pregnancy to at other times of their lives and may, therefore, require different interventions. I presented evidence that increased medical intervention and testing during pregnancy for women with type 1 diabetes can be expected and reassuring, but also has the potential to increase distress and reduce the positive experiences of pregnancy for some women. Finally, in study one, I showed there may be higher levels of anxiety and impacts on mental health during the pregnancy journey for women with type 1 diabetes and that readily accessible, up-to-date, pregnancy information, and health care professional, family and peer support, are all important.

In study two, I focused on the Contemplation phase of this journey and presented evidence from the literature that pre-pregnancy planning and preparation for pregnancy are key to the reduction of adverse outcomes for women with type 1 diabetes and their babies. Despite this, attendance rates at pre-pregnancy counselling remain persistently low. The literature review revealed that a person-centred approach, recognising women's expertise in their own type 1 diabetes, is important. Finding a balance between presentation of risk information and the positive support in relation to the chances of a healthy pregnancy,

improves communication between health care professionals and women with type 1 diabetes. This, in turn, supports self-efficacy and encourages a sense of personal optimism about the pregnancy journey. All of these factors together, might ultimately increase the likelihood of women's attendance at pre-pregnancy counselling. Based on these findings, I developed a prototype Contemplating Pregnancy in Diabetes Communication Support Questionnaire, which is now ready for further testing. I recommended that once fully tested, this be available in both print and digital platforms, to meet the need for flexible access to pregnancy information.

In this final study number three, I present a meta-synthesis of the current themes in the qualitative research relating to the use of internet-based programmes and resources to deliver type 1 diabetes and pregnancy information and support. I present the results of the meta-synthesis and suggest implications for practice. Qualitative studies were chosen, given the primary focus of this mixed-method thesis, has overall been of a qualitative nature.

RESEARCH QUESTIONS

There were a number of questions relevant to this meta-synthesis, as follows:

1. What is the evidence for the use of internet-based programmes and resources in type 1 diabetes and pregnancy? How useful is this research? Are there any gaps?
2. Are internet-based pregnancy programmes and resources beneficial for women with type 1 diabetes? If so, in what ways?
3. What kinds of internet-based programmes and resources are the most beneficial and why?
4. What are the priorities for future research?

INTRODUCTION

The Internet and associated digital tools for seeking, communicating, and using information, have increasingly become part of human social actions since the 1990's. In addition, the growing interest in eHealth has increased research and generated new ideas about health literacy (Huhta et al., 2018). eHealth can be defined as the use of emerging information and communication technology, especially the Internet, to improve or enable health and health care (Huhta et al., 2018).

Internet-based programmes and online modes of health services delivery via the Internet, have increased in popularity as potential tools to support people with diabetes (Peterson, 2014). The reasons for this include: the ability for enhanced communication with a provider; people with diabetes can independently assess and manage their own diabetes; moreover, there are associated cost savings (Peterson, 2014). The rate of development and advances in mobile phone technology and its applications, coupled with strong growth of telecommunication technology, offers people improved access to healthcare information to make their lives easier, and enables efficient self-care, via their smart phone. Mobile technology can be used by both health care professionals and people with diabetes (David & Rafiullah, 2016). Social media can be defined as a group of internet-based applications that build on the ideological and technological foundations of Web 2.0 and that allow the creation and exchange of user-generated content (Kaplan, 2015). These include platforms such as Facebook, Instagram, YouTube and Twitter. It has been suggested that social networks can impact behaviour change and that health improvements in one person may spread to another, through a viral process (Shaw & Johnson, 2011). Popular online social networks such as Facebook may mirror these kinds of behaviours, with the added advantage of being able to connect easily to larger numbers of people (Shaw & Johnson, 2011).

In chapter 1, I reported that some women with type 1 diabetes use the Internet to seek diabetes related information and communicate with other women (Sparud-Lundin et al., 2011a), and that they find this support from women in similar situations creates a sense of community and belonging. It was suggested that where there is reliable information available, the Internet can provide access to health care professionals, as well as offer interactive support and social networking during pregnancy and beyond (Sparud-Lundin, Ranerup, et al., 2011). In study one, I also showed that women were accessing the diabetes counselling online services during contemplation of pregnancy, and that they continued to do so throughout the pregnancy journey – seeking knowledge, as well as health care professional and peer support (Edwards et al., 2016).

It was revealed in the thematic analysis in study one (Edwards et al., 2016) that some women might prepare for pregnancy earlier than presumed, through seeking information from sources such as social media and internet-based resources, and that this might be meeting the need for both emotional and practical support. Conversely, the analysis found that information and stories from peers and other online sources may be detrimental if incorrect information, or negative experiences, are shared, leading to pessimism (Edwards et al., 2016). This meta-synthesis of the qualitative literature aims to facilitate the identification of further research priorities in this field, and inform health care professionals about current evidence for the use of Internet-based programmes and resources to support women with type 1 diabetes during the pregnancy journey.

INCLUSION AND EXCLUSION CRITERIA

This meta-synthesis considers qualitative studies with a focus on women with type 1 diabetes at any stage of the pregnancy journey, from Contemplation to Motherhood, which mention the use of the Internet, internet-based resources and programmes, websites, social media, mobile Applications, eHealth and telemedicine, in their interventions. In general,

studies considering the use of the Internet in type 1 diabetes, where pregnancy and motherhood were mentioned, were also included. Studies which were purely quantitative, and those where type 1 diabetes was not included, were excluded. There were no date or language restrictions in the search terms.

TYPES OF INTERVENTIONS/PHENOMENA OF INTEREST

The qualitative component of this meta-synthesis considers as phenomena of interest, the experiences of pregnancy and motherhood for women with type 1 diabetes, and the use of the internet-based programmes and resources to support their wellbeing and diabetes education needs during the pregnancy journey. This includes women's experiences of knowledge seeking, peer support and health care professional relationships in using Internet based programmes, the development and evaluation of Internet based programmes and any other related issues.

TYPES OF STUDIES

The meta-synthesis considered studies that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, thematic analysis, focus groups, interviews, and action research. Descriptive qualitative studies that describe the experience or describe the effects of the experience were also considered.

RESEARCH TEAM AND PROCESS

The research team for this meta-synthesis consisted of myself and my 3 supervisors - Professor Deborah Turnbull, Professor Michael Horowitz and Dr William Polonsky. Dr Melissa Oxlad contributed from the outset with advice on methodology. Details of the protocol and the proposed conduct of the meta-synthesis were discussed at the first meeting with Dr Oxlad. During the analysis, meetings were held regularly with my primary supervisor, to track progress and provide feedback on the emerging themes and categories. The other two members of the research group were invited to provide comment at the draft

stage of this chapter, to provide comments on the process, the results and conclusions of the meta-synthesis.

SEARCH STRATEGY

Literature Review Terms

The data bases were chosen at the advice of a research librarian, being the most likely to contain relevant studies. The literature search strategy was formalised first using MeSH searches in PubMed to select appropriate search terms under the headings of: 'Diabetes' 'Pregnancy' 'Wellbeing' and 'Digital Health'. This included searches across CINAHL, Embase, PubMed and PsycINFO. The title and abstract terms were kept as close as possible across all databases. As I was well informed about the current literature in this field due to my two previous literature searches for studies one and two, I chose to retain the mental health terms in the initial search, as they might have revealed qualitative studies relevant to internet-based interventions. I chose not to restrict the terms to qualitative studies only, as again, with the small number of studies in this field, I felt that some mixed-method studies might be missed. As per the table below, a search was carried out with column 1 and column 2 and column 3 and column 4; followed by searching only column 1 and column 2 and column 3. Search terms were chosen as per each databases method.

Table 7: Literature Review Search Terms

PubMed

Diabetes	Pregnancy	Wellbeing	Digital Health
"Diabetes Mellitus, Type 1"[mh:noexp] OR "Diabetes Mellitus"[mh:noexp] OR "diabetes mellitus, type 2"[mh:noexp] OR "Latent Autoimmune Diabetes in	"fetal development"[tiab] OR "foetal development"[tiab] OR Parity[tiab] OR "Periconceptual Period"[tiab] OR "Perinatal care"[mh] OR perinatal[tiab] OR	"Depression, Postpartum"[mh] OR "Postpartum Depression"[tiab] OR "Mental Health"[tiab] OR "Anxiety"[mh:noexp] OR "anxiety disorders"[mh:noexp]	"Internet"[mh] OR "Internet" [tiab] OR "Website"[mh] OR "Website" [tiab] OR "Social Media"[mh] OR "Social Media"[tiab] OR "Mobile Applications"[mh] OR

Adults"[mh] OR diabetes[tiab] OR diabetic[tiab] OR "Diabetes Mellitus, Gestational"[tiab] OR "type 1 diabetes"[tiab] OR "type one diabetes"[tiab] OR "type 2 diabetes"[tiab] OR "type two diabetes"[tiab]	"Prepregnancy Care"[tiab] OR "Pre-Pregnancy Care"[tiab] OR postnatal[tiab] OR "post natal"[tiab] OR "Prenatal care"[tiab] OR "maternal fetal relations"[mh] OR OR "Pregnancy Trimesters"[mh] OR Postpartum[tiab] OR "pregnancy"[mh:noexp] OR "gravidity"[mh] OR "labor, obstetric"[mh] OR "parity"[mh] OR "parturition"[mh] OR "placentation"[mh] OR "Pregnancy in Adolescence"[mh] OR "Pregnancy Maintenance"[mh] OR "Pregnancy Outcome"[mh] OR "Pregnancy, High-Risk"[mh] OR "Pregnancy, Multiple"[mh:noexp] OR "Pregnancy, Unplanned"[mh] OR Childbirth[tiab] OR "Pregnancy, Unwanted"[mh] OR pregnan*[ti] OR pregnancy[tiab] OR "Prenatal Care"[tiab] OR "Pre-Natal Care"[tiab] OR gravidity[tiab] OR "abortion, habitual"[mh:noexp] OR "abortion, spontaneous"[mh:noexp] OR miscarriage[tiab] OR miscarry[tiab] OR "pregnancy in diabetics"[mh] OR "pregnancy in diabetes"[tiab] OR	OR anxiety[tiab] OR "mental health"[tiab] OR "mental health"[mh] OR "Quality of Life"[mh] OR "Quality Of Life"[tiab] OR "emotional adjustment"[tiab] OR "depression"[mh] OR depression[tiab] OR "Self Efficacy"[mh] OR Self Efficacy[tiab] OR "Self-Efficacy"[tiab] OR "Self Care"[mh] OR "Self Care"[tiab] OR "Self-Care"[tiab] OR "Social Support"[mh] OR "Social Support"[tiab] OR "Peer Influence"[mh] OR "Professional-Patient Relations"[mh:noexp] OR "Psychological Well-Being"[tiab] OR "Maternal-Child Health"[tiab] OR Parenthood[tiab] OR Motherhood[tiab] OR "Parent-Child Relations"[tiab] OR "Psychosocial Support"[tiab] OR "Emotional Adjustment"[tiab]	Patient Portals [mh] OR "Blog"[mh] OR "Peer Influence"[mh] OR "Telemedicine"[mh] OR "Telemedicine"[tiab]

	"Maternal Behavior"[mh] OR "Parenting"[mh] OR Parenting[tiab] OR "Breast Feeding"[mh] OR "Breast Feeding"[tiab] OR "Obstetric Care"[tiab] OR Labor[tiab] OR Labour[tiab] OR "Fetal Distress"[tiab] OR "Foetal Distress"[tiab] OR "Fetal Macrosomia"[tiab] OR "Foetal Macrosomia"[tiab]		

CINAHL Database

Diabetes	Pregnancy	Wellbeing	Digital Health
MH "Diabetes Mellitus+" OR TI "Diabetes Mellitus" OR AB "Diabetes Mellitus" OR MH "Pregnancy in Diabetes+" OR TI "Pregnancy in Diabetes" OR AB "Pregnancy in Diabetes" OR MH "Diabetes Mellitus, Gestational" OR TI "Diabetes Mellitus, Gestational" OR AB "Diabetes Mellitus, Gestational" OR MH "Diabetes Mellitus, Type 1+" Or TI "Diabetes Mellitus, Type 1" OR TI "type 1 diabetes" OR AB "type 1 diabetes" OR TI "type one diabetes" OR AB "type one diabetes" OR TI "type 2 diabetes" OR AB "type two diabetes" OR AB "Diabetes	MH "Fetal Development+" OR TI "Fetal Development" OR AB "Fetal Development" OR TI "Foetal Development" OR AB "Foetal Development" OR MH "Pregnancy in Adolescence" OR MH Parity OR TI Parity OR AB Parity OR MH "Periconceptual Period" OR TI "Periconceptual Period" OR AB "Periconceptual Period" OR TI Postpartum OR AB Postpartum OR MH "Postnatal Period+" OR TI Postnatal OR AB Postnatal OR TI "Post Natal" OR AB "Post Natal" OR MH "Pregnancy+" OR TI Pregnan* OR AB Pregnan* OR MH "Childbirth+" OR TI	MH "Depression" OR TI Depression OR AB Depression OR MH "Depression, Postpartum" OR TI "Postpartum Depression OR AB "Postpartum Depression" OR MH "Anxiety" OR TI Anxiety OR AB Anxiety OR MH "Mental Health" OR TI "Mental Health" OR AB "Mental Health" OR MH "Psychological Well-Being" OR TI "Psychological Well-Being" OR AB "Psychological Well-Being" OR MH "Mental Status" OR MH "Social Determinants of Health" OR MH "Maternal-Child Health" OR TI "Maternal-Child	MH "Internet+" OR TI "Internet" OR AB "Internet" OR MH "Website+" OR TI "Website" OR AB "Website" OR MH "Social Media" OR TI "Social Media" OR AB "Social Media" OR MH "Mobile Applications+" OR MH "Patient Portals+" OR TI "Patient Portals" OR MH "Blog+" OR TI "Blog" OR MH "Peer Influence" OR TI "Peer Influence" OR MH "Telemedicine+" OR TI "Telemedicine" OR AB "Telemedicine"

Mellitus, Type 1" OR MH "Diabetes Mellitus, Type 2" OR TI "Diabetes Mellitus, Type 2" OR AB "Diabetes Mellitus, Type 2" OR MH "Diabetic Patients" OR MH "Glycemic Control"	Childbirth OR AB Childbirth OR MH "Pregnancy, High Risk" OR MH "Pregnancy Trimesters+" OR MH "Pregnancy, Unplanned" OR MH "Pregnancy, Unwanted" OR MH "Maternal-Child Care+" OR MH "Obstetric Care" OR TI "Obstetric Care" OR AB "Obstetric Care" OR MH "Delivery, Obstetric" OR MH "Vaginal Birth+" OR MH "Intrapartum Care" OR MH Labor+ OR MH "Labor, Induced" OR MH "Labor Support" OR MH "Management of Labor" OR TI Labor OR AB Labor OR TI Labour OR AB Labour OR MH "Perinatal Care" OR TI Perinatal OR AB Perinatal OR MH "Postnatal Care" OR TI "Postnatal Care" OR AB "Postnatal Care" OR MH "Prenatal Care" OR TI "Prenatal Care" Or AB "Prenatal Care" OR TI "Pre-Natal Care" OR AB "Pre-Natal Care" OR MH "Prepregnancy Care" Or TI "Prepregnancy Care" Or AB "Prepregnancy Care" Or TI "Pre-Pregnancy Care" Or Ab "Pre-Pregnancy Care" Or MH "Abortion,	Health" OR AB "Maternal-Child Health" OR MH "Reproductive Health" OR MH "Sexual Health" OR MH "Women's Health" OR MH "Quality of Life" OR TI "Quality Of Life" OR AB "Quality of Life" OR MH "Self-Efficacy" OR TI "Self-Efficacy" OR AB "Self-Efficacy" OR TI "Self Efficacy" OR AB "Self Efficacy" OR TI "Self Care" OR AB "Self Care" OR TI "Self-Care" OR AB "Self-Care" OR MH "Parenthood" OR TI Parenthood OR AB Parenthood OR MH "Motherhood" OR TI Motherhood OR AB Motherhood OR MH "Family Coping" OR MH "Maternal Behavior" OR MH "Maternal Behaviour" OR MH "Parent-Child Relations+") OR TI "Parent-Child Relations" OR AB "Parent-Child Relations" OR MH "Patient-Family Relations" OR MH "Peer Pressure" OR MH "Professional-Client Relations" OR MH "Professional-Family Relations" OR MH "Physician-Patient Relations" OR MH "Nurse-Patient Relations" OR MH "Attitude to Breast Feeding" OR MH	

	Spontaneous" OR MH "Childbirth, Premature" OR MH "Fetal Distress" OR TI “Foetal Distress” Or AB “Foetal Distress” OR MH "Fetal Macrosomia" OR TI “Fetal Macrosomia” Or AB “Fetal Macrosomia” OR MH “Foetal Macrosomia” OR TI “Foetal Macrosomia” OR AB “Foetal Macrosomia” OR MH "Dystocia+" OR MH "Breast Feeding+"	"Health Beliefs" OR MH "Psychosocial Aspects of Illness" OR MH "Social Inclusion" OR MH "Social Isolation" OR MH "Social Participation" OR MH "Support, Psychosocial" OR TI “Psychosocial Support” OR AB “Psychosocial Support” OR TI “Emotional Adjustment” OR AB “Emotional Adjustment”	

EMBASE

Diabetes	Pregnancy	Wellbeing	Digital Health
Diabet*:ti,ab OR ‘Diabetes Mellitus’:ti,ab OR ‘insulin dependent diabetes’:ti,ab OR ‘insulin dependent diabetes’:ti,ab OR ‘diabetes control’:ti,ab OR ‘pregnancy diabetes mellitus’:ti,ab OR ‘diabetes, pregnancy’ OR ‘pregnancy in diabetics’	pregnancy/de OR Pregnan*:ti,ab OR Gravdity:ti,ab OR Parity:ti,ab OR pregnancy:ti,ab OR ‘fetus development’/de OR ‘fetus development’:ti,ab OR ‘fetal development’:ti,ab OR ‘foetal development’:ti,ab OR ‘prenatal period’/de OR ‘prenatal care’/de OR ‘prenatal care’:ti,ab OR 'prenatal period'/exp OR ‘prenatal care’:ti,ab OR 'macrosomia'/exp OR ‘fetal macrosomia’:ti,ab OR ‘foetal macrosomia’:ti,ab OR 'postnatal care'/exp OR postnatal:ti,ab OR ‘postnatal care’:ti,ab OR Postpartum:ti,ab OR Childbirth:ti,ab OR 'breast feeding'/de OR ‘breast feeding’:ti,ab OR breastfeeding:ti,ab OR 'spontaneous abortion'/de OR miscarriage:ti,ab OR miscarry:ti,ab OR ‘perinatal care’/de OR ‘perinatal care’:ti,ab OR ‘high risk pregnancy’/de OR ‘obstetric delivery’/de OR ‘obstetric care’:ti,ab OR Labor:ti,ab OR Labour:ti,ab OR ‘pregnancy complication’/de OR	'depression, postpartum'/exp OR 'depression, postpartum' OR 'postpartum depression':ti,ab OR 'mental health':ti,ab OR anxiety:ti,ab OR 'quality of life':ti,ab OR depression:ti,ab OR 'self-efficacy':ti,ab OR 'self care':ti,ab OR 'self-care':ti,ab OR 'social support':ti,ab OR 'psychological well-being':ti,ab OR 'maternal-child health':ti,ab OR parenthood:ti,ab OR motherhood:ti,ab OR 'parent-child relations':ti,ab OR 'psychosocial support':ti,ab OR 'emotional adjustment':ti,ab OR 'perinatal depression'/exp OR 'perinatal depression' OR 'edinburgh postnatal depression scale'/exp OR 'edinburgh postnatal depression scale' OR 'depression assessment'/exp OR 'depression assessment' OR 'child parent relation'/exp OR 'child parent relation' OR 'maternal behaviour'/exp OR 'maternal behaviour' OR 'maternal behavior'/exp OR 'maternal behavior' OR 'mother child	‘Internet’:ti,ab OR ‘Website’:ti,ab OR ‘Social Media’:ti,ab OR ‘Mobile Applications’:ti,ab OR ‘Patient Portals’:ti,ab OR ‘Blog’:ti,ab OR ‘Peer Influence’:ti,ab OR ‘Telemedicine’:ti,ab

	‘pregnancy outcome’/de	relation'/exp OR 'mother child relation' OR 'social support'/exp OR 'social support' OR 'anxiety'/exp OR anxiety OR 'professional-patient relationship'/exp OR 'professional-patient relationship' OR 'diabetes educator'/exp OR 'diabetes educator' OR 'self concept'/exp OR 'self concept' OR 'quality of life'/exp OR 'quality of life' OR 'mental health'/exp OR 'mental health' OR 'psychosocial care'/exp OR 'psychosocial care'	

PsycInfo

Diabetes	Pregnancy	Wellbeing	Digital Health
Diabetes.sh,ti,ab OR Diabetes mellitus.sh,ti,ab OR Diabet*.ti,ab OR gestational diabetes.ti,ab OR type 1 diabetes.ti,ab OR type 2 diabetes.ti,ab OR type one diabetes.ti,ab OR type two diabetes.ti,ab OR diabetic.ti,ab OR Diabetes Mellitus, Gestational.ti,ab	Pregnancy.sh OR Birth.sh OR Pregnancy Outcomes.sh OR Caesarean Birth.sh OR Natural Childbirth.sh OR Obstetrical complications.sh OR Perinatal Period.sh OR Postnatal Period.sh OR Birth Injuries.sh OR Prenatal care.sh OR Premature Birth.sh OR Spontaneous Abortion.sh OR Spontaneous Abortion.ti,ab OR Birth Injuries.sh OR Birth Weight.sh OR Obstetrical Complications.sh OR Breast Feeding.sh OR Breastfeeding.ti,ab OR Lactation.sh OR fetal development.ti,ab OR foetal development.ti,ab OR	Postpartum Depression.sh OR Postpartum depression.ti,ab OR Postnatal depression.ti,ab OR Major Depression.sh OR Depression.sh,ti,ab OR Attachment Behavior.sh OR Mother Child Relations.sh OR Postnatal Period.sh OR Anxiety.sh,ti,ab OR Anxiety Disorders.sh OR Fear.sh OR Guilt.sh OR Shame.sh OR Stress.sh OR Quality Of Life.sh,ti,ab OR Life Changes.sh OR Self-Efficacy.sh OR Peer Relations.sh OR Peers.sh OR Parent Child Relations.sh OR Family Relations.sh	Internet.sh,ti,ab OR Website.sh,ti,ab OR Social Media.sh,ti,ab OR Mobile Applications.sh,ti,ab OR Patient Portals.sh,ti,ab OR Blog.sh,ti,ab Peer Influence.sh,ti,ab OR Telemedicine.sh,ti,ab

	Parity.ti,ab OR Periconceptual Period.ti,ab OR perinatal.ti,ab OR Prepregnancy Care.ti,ab OR Pre-Pregnancy Care.ti,ab OR postnatal.ti,ab OR post natal.ti,ab OR Prenatal care.ti,ab OR Postpartum.ti,ab OR Childbirth.ti,ab OR pregnan*.ti,ab OR Prenatal Care.ti,ab OR Pre-Natal Care.ti,ab OR gravidity.ti,ab OR miscarriage.ti,ab OR miscarry.ti,ab OR pregnancy in diabetes.ti,ab OR Parenting.ti,ab OR Breast Feeding.ti,ab OR Obstetric Care.ti,ab OR Labor.ti,ab OR Labour.ti,ab OR Fetal Distress.ti,ab OR Foetal Distress.ti,ab OR Fetal Macrosomia.ti,ab OR Foetal Macrosomia.ti,ab	OR Parenting.sh OR Mental Health.ti,ab OR Emotional adjustment.ti,ab OR Self Efficacy.ti,ab OR Self-Efficacy.ti,ab OR Self Care.ti,ab OR Self-Care.ti,ab OR Social Support.ti,ab OR Psychological Well-Being.ti,ab OR Maternal-Child Health.ti,ab OR Parenthood.ti,ab OR Motherhood.ti,ab OR Parent-Child Relations.ti,ab OR Psychosocial Support.ti,ab OR Emotional Adjustment.ti,ab	

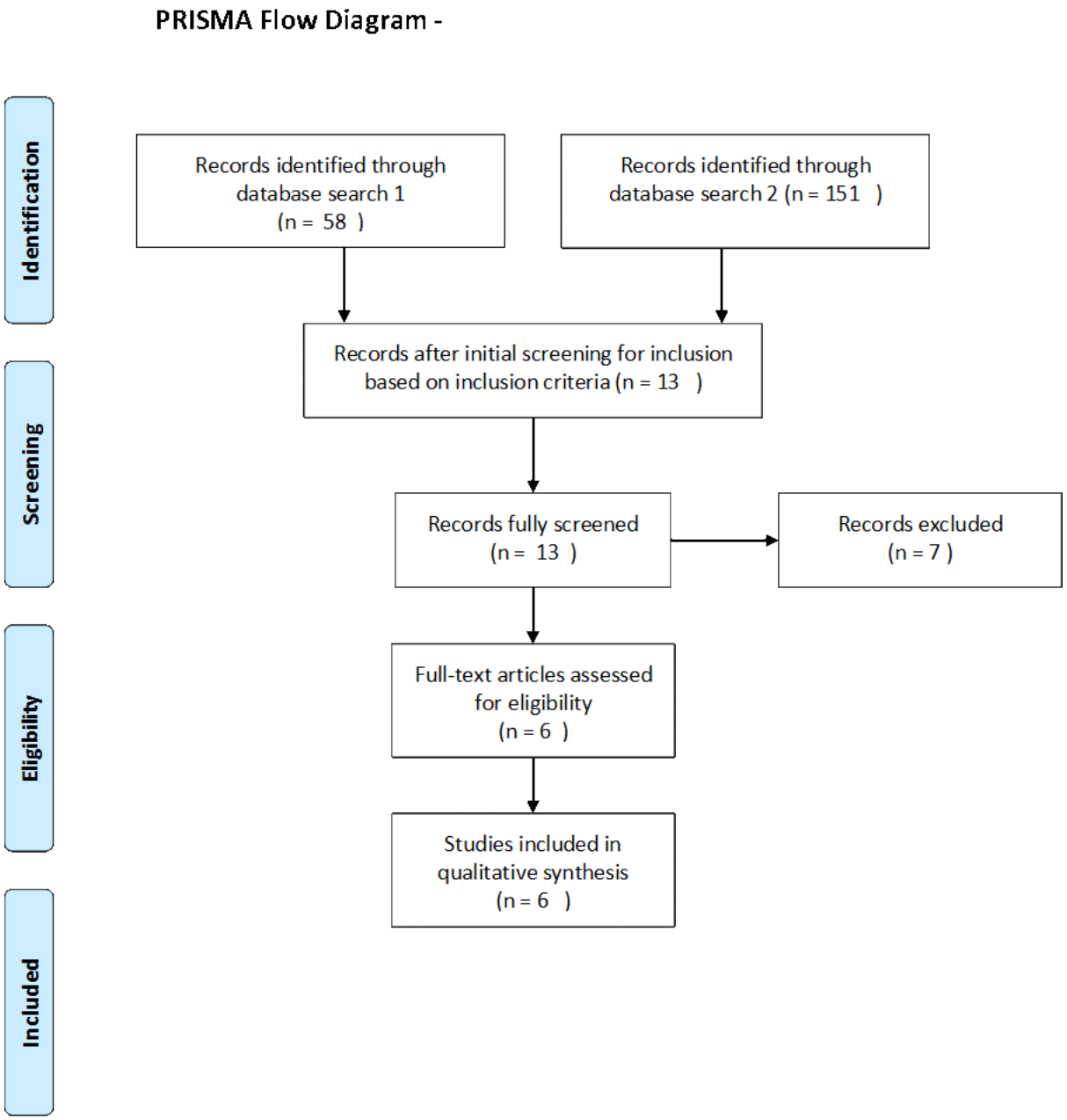
LITERATURE REVIEW RESULTS

58 results were returned in search 1 and 151 results were returned in search 2. Of these, 13 papers were considered initially to be potentially relevant to this meta-synthesis. After discussion with my primary supervisor, it was agreed that 7 of these papers should be excluded, as they contained quantitative methodology. This left 6 papers for the meta-synthesis.

Four of these papers related to a single overarching study – the development and testing of the MODIAB-Web programme. The papers related to this study included an explorative and descriptive study considering Internet use, needs and expectations, regarding web-based information and communication, in childbearing women with type 1 diabetes; followed by a focus group study to examine their prototype website; presentation of the participatory design process; and an exploratory case study analysis.

The other 2 papers included a focus group study around development of a preconception DVD and website resource for women with diabetes; and a grounded theory study which related more broadly to the transitions of young women with type 1 diabetes, of which pregnancy and motherhood were included.

Table 2: PRISMA Flow Diagram for Literature Review



DATA EXTRACTION AND META-SYNTHESIS

Assessment of Methodological Quality

To begin the process of meta-synthesis, I firstly assessed the 6 eligible papers from the literature review for methodological rigor and quality, based around the standardized critical appraisal checklist from the JBI Model for meta-synthesis. The JBI approach aims to ultimately develop statements that can be used as recommendations in guiding practitioners

and policy makers, taking a meta-aggregative approach to the synthesis of qualitative evidence. This gives adequate focus on traditional qualitative research, while being based on the process of systematic review (Joanna Briggs Institute system for the unified management, assessment and review of information (JBI SUMARI), 2014). Based on this, I independently assessed each of the 6 potential papers, using the checklist below to determine inclusion:

1. Is there congruity between the stated philosophical perspective and the research methodology?
2. Is there congruity between the research methodology and the research question or objectives?
3. Is there congruity between the research methodology and the methods used to collect data?
4. Is there congruity between the research methodology and the representation and analysis of data?
5. Is there congruity between the research methodology and the interpretation of results?
6. Is there a statement locating the researcher culturally or theoretically?
7. Is the influence of the researcher on the research, and vice- versa, addressed?
8. Are participants, and their voices, adequately represented?
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

Each study was then scored to 3 possible levels of credibility as follows:

1. Unequivocal (findings are accompanied by an illustration that is beyond reasonable doubt and, therefore, not open to challenge);

2. Credible (findings are accompanied by an illustration lacking clear association with it and are, therefore, open to challenge); or

3. Unsupported (findings are not supported by data).

Data extraction and synthesis then included a three-step process based on the JBI methodology:

1. Extraction of findings from all of the 6 papers, with at least one accompanying illustration, and establishment of a level of credibility for each 'finding' (theme) – presented in table 1. A 'finding' is defined as a verbatim extract of each author's analytic interpretation accompanied by an 'illustration' - either a participant voice, or fieldwork observations, or other data;
2. Developing categories for these findings that were sufficiently similar, with at least two 'findings' per 'category'; and
3. Developing one or more synthesized findings, of at least two categories.

Definitions

The operational definitions that characterize meta-aggregation describe the data to be synthesized, and explain what each step looks like as follows (Joanna Briggs Institute system for the unified management, assessment and review of information (JBI SUMARI), 2014):

Finding: A finding is a verbatim extract of the author's analytic interpretation of their results or data. In undertaking the synthesis component of a meta-aggregative review, each finding that is extracted from a paper is accompanied by an illustration.

Illustration: An illustration is defined as a direct quotation of a participant's voice, field-work observation or other supporting data from the paper.

Category: A category is a brief description of a key concept arising from the aggregation of two or more similar findings, in the presence of an explanatory statement that conveys the whole inclusive meaning of a group of similar findings. When two or more findings are combined to form a category, a category description is also created.

Category description: A category description is defined as an explanatory statement that conveys the whole, inclusive meaning of a group of similar findings.

Synthesized finding: A synthesized finding is an overarching description of a group of categorized findings. Synthesized findings are expressed as 'indicatory' statements that can be used to generate recommendations for policy or practice. As with categories, a description is created for each synthesized finding.

Synthesized finding description: The description for a synthesized finding is defined as an explanatory statement that conveys the whole, inclusive meaning of a group of similar categories.

RESULTS

Assessment of Methodological Quality and Data Extraction

I worked through each paper, reading the text and seeking to assess each paper against the 10 points above. Based on whether there were illustrations pertaining to each finding, I assessed and rated 5 studies as Unequivocal and 1 as Credible, as below, and, therefore, selected all 6 for inclusion in the meta-analysis.

Table 8: Paper ratings and sample illustrations from each

PAPER TITLE AND DATE	STUDY TYPE	RATING	SAMPLE ILLUSTRATIONS – relevant sample of an illustration from the paper
Preconception Counselling Resource for Women with Diabetes - 2015	Focus Group Study, raising awareness of the importance of pregnancy planning among women with diabetes and health care professionals, creating a DVD resource, later converted to a website www.womenwithdiabetes.net	Credible - (note this study was later evaluated and reported on in the literature, but used only quantitative methods so was not included)	"This project has highlighted the importance of user/patient involvement in the creation of educational resources. Ideas and plans for the resource which the team had discussed prior to the focus groups were altered substantially once focus group feedback was considered. For example, the team had considered the inclusion of video footage of healthcare professionals within the resource advising women on planning pregnancy. Women rejected this idea, instead wanting a real lives approach which led to the resource having a 'cast' of eight women with diabetes women with diabetes during the design and development phase of both the DVD and the subsequent website development led to the creation of a highly acceptable preconception counselling resource"

Young Women with diabetes: Using Internet communication to create stability during life transitions - 2007	Grounded Theory study: Aim to explore and describe the strategies young women with type 1 diabetes used to manage transitions in their lives	Unequivocal	'I probably sound like a lunatic, but now I know that the web sites are there, I would check that every day. There might not be anything on it, but just the fact, I don't know, it is almost like a bit of a release and quite often I put some questions up on the forum they have got and straight away, people that you know have had it for a long time, or they know what you are going through, so they will put in what they think and that. It is really a great outlet. That is why I think it is fantastic.'
Internet use, needs and expectations of web-based information and communication in childbearing women with type 1 diabetes -2011	Internet-based survey with an explorative and descriptive design; analysed with descriptive and analytical statistics and open answers with a directed content analysis	Unequivocal	'Instead of visits, it would have been convenient to be able to check with people over the phone or perhaps online, simply to verify blood sugar levels, insulin doses, and the like. Mainly during early pregnancy, when there are no other checks on the child. Also, before the pregnancy is public knowledge, people prefer not to have to go to the hospital for check-ups too often, as it makes them feel as if they are under suspicion at work, which is stressful. In other words, a way of managing and looking after women, particularly in early pregnancy, that is a little more convenient and "discreet", but naturally without imparting a sense that the quality of care is being compromised.'
Prototype for Internet support of pregnant women and mothers with type 1 diabetes: focus group testing - 2012	Focus Group Study to examine the internet-based support programme	Unequivocal	'Sure, those who work with diabetes and pregnancy know the facts about how diabetes works, but they can never understand the feelings that are involved or how you make it work in your everyday life. They can only provide tips about how others deal with it. It is easier to talk with someone who is actually in the exact same situation'
Person-Centred Web Support to Women with type 1 diabetes in Pregnancy and Early Motherhood – the Development Process - 2017	Participatory Design process for the internet-based support programme	Unequivocal	The application of a participatory design and a general process map for development of Internet-based support has safeguarded person-centeredness for these women. Professional actors (researchers and clinicians in collaboration with technicians) were necessary in the development process, but more important were the representatives of the users, mothers who had type 1 diabetes and had recently experienced childbearing.
Web-based Intervention for Women with type 1 diabetes in pregnancy and early motherhood: Critical	Exploratory case-study, descriptive and content analysis	Unequivocal	Dialogue—Example 1 Woman 1: "As a diabetic, having kids isn't a walk in the park but I've managed twice before with completely perfect kids…this pregnancy has been really tough – with high blood pressure and low sugar but after a lot of messing about, it's sorted itself out now."

Analysis of Adherence to Technological Elements and Study Design - 2018			Woman 2: "I'm so inspired and motivated when I hear people like you – congratulations on pregnancy number three! I'm in my first but we're almost the same age and I've been a diabetic for 22 years. My biggest worry is the hypos. I hate them and I worry the baby can feel them. Once all its organs are ok and I know it can produce insulin and has a liver with a glycogen store, I'll be calmer. My levels aren't low all the time – my HBA1C is 7.9 so it has to be lowered. One side effect of my managing to lower it is that I'm more insulin sensitive. But I know that changes in different stages of pregnancy. Was it obvious in your other pregnancies – in which case, when might you have become more insulin resistant?

Once I confirmed that the 6 studies were suitable for inclusion through this process, I identified the primary findings of each study through reading and re-reading of each paper. I firstly recorded these findings as closely as possible to each authors' words, to represent each study's primary findings and intent. Where possible, I extracted these findings verbatim from each study, and included at least one illustration of these. I identified text as 'findings' based on commonly presented headings, subheadings, and themes as stated by the authors of each paper. Such themes were often identified further through presentation of discussion within the body of each paper.

After identifying the individual findings, I sought to find common findings across papers. I then developed categories that appeared to represent these groups of common findings, through either conceptual likeness - where a common theme was found to exist across findings, and descriptive likeness - where similar terminology was used across findings. Some categories therefore related to more than one of the papers, but not every category was present in every paper. The categories were also derived through analysis of the entire paper, including the introduction, methods and discussion, not just the results.

This process of aggregating findings across different studies to create categories, has been described as similar to procedures used in basic qualitative research methods, including constant comparative analysis and thematic analysis (Peters, Lisy, Riitano, Jordan, & Aromataris, 2015). After reading each paper and re-reading, to identify the findings and develop the categories, I then considered the ways in which these categories linked, to form three synthesized findings present across the 6 papers in varying degrees:

1) Arguments for the use of internet-based resources and programmes to address the issues in pregnancy and type 1 diabetes;
2) Development processes for internet-based resources and programmes in pregnancy and type 1 diabetes; and/or
3) Evaluation of internet-based resources and programmes in pregnancy and type 1 diabetes and recommendations for further work.

The following section describes the categories, developed from the individual findings, summarised within each of the 3 synthesized findings:

1) Argument for the use of internet-based resources and programmes to address the issues in pregnancy and type 1 diabetes

EXTRAORDINARILY DEMANDING - pregnancy for women with type 1 diabetes is more demanding than usual.

KNOWLEDGE - There is a need for increased knowledge about the importance, reasons for and what is included in, pre-pregnancy counselling – for both women with type 1 diabetes and health care professionals.

EMPOWERMENT - there is a need for more support, skills training and education, for health care professionals in providing pre-pregnancy counselling.

POSITIVE SUPPORT - pregnancy information should be provided in a positive, motivating and supportive manner, both in person and online.

COMMUNICATION - positive and balanced communication is needed between health care professionals and women with type 1 diabetes.

AUTONOMY - internet-based support means women can access information at a time that suits them and maintain control of their diabetes and their lives.

SOCIAL SUPPORT AND UNDERSTANDING - internet-based programmes which include forums and social media, enable support from other women with type 1 diabetes, thereby reducing isolation and distress.

RELATIONSHIPS - using internet-based communication to share issues and concerns with peers and health care professionals, avoids negative impacts on loved ones and/or negative responses to issues raised about diabetes and pregnancy.

REDUCED ANXIETY AND DISTRESS - internet-based support can offer reassurance, to lower anxiety and reduce isolation, and it is easier to raise sensitive issues such as pregnancy and contraception.

OPTIMISM AND HOPE - being able to communicate easily with peers, seek relevant knowledge, and feel in control of these behaviours, leads to growth in self-confidence and empowerment to make decisions.

SELF-ESTEEM, SELF-EFFICACY AND ANONIMITY-– internet-based resources allow women to determine when, where and what information and support they seek; preserving anonymity where desired.

2) Development processes for internet-based programmes and resources in pregnancy and type 1 diabetes

PERSON CENTRED - it is recommended to include women's voices, stories and experiences, in the development of internet-based resources and programmes, with a participatory approach.

POSITIVE SUPPORT - pregnancy information included in internet-based programmes and resources should be offered in a positive, motivating and supportive manner.

ACCESSIBIILTY TO INFORMATION AND SUPPORT – internet-based programmes and resources should include flexibility in access, with a variety of information sources and platforms.

BALANCE – offer a balance between pregnancy risk information and becoming and being a mother in internet-based resources and programmes.

QUALITY OF INFORMATION – needs to be reliable information, guided by health care professional experts and women with diabetes, with validated links and updates to information.

WOMEN AS MOTHERS' – use internet-based programmes to offer opportunities for women to engage in conversations around becoming and being a mother as well as giving diabetes and pregnancy risks and management.

3) Evaluation of internet-based programmes and resources in pregnancy and type 1 diabetes and recommendations for future work

EQUITY – understanding and researching how to reach hard-to-reach and vulnerable groups using internet-based technologies is needed as a priority.

UP-TO-DATE AND RELEVANT TECHNOLOGY – maintain expertise with changes in digital health, diabetes management tools and variability between users' skills and knowledge in using digital tech.

TECHNOLOGY AND STUDY DESIGN – consider the changing nature of technology and how study design might be impacted. Keep design simple and consider integrating with existing social media.

LIMITED TARGET POPULATION – be realistic when calculating your sample size. Be aware of limited target population. Design your study with multiple methods of analysis.

PEER SUPPORT – consider engaging a study facilitator from your target group. A larger critical mass of participants may be needed to account for active vs passive users.

COST ANALYSIS - consider all potential costs and issues in development and evaluation of internet-based programmes, including ongoing costs and provision of resources such as moderators.

SECURITY AND CONFIDENTIALITY OF DATA – this is an important consideration in the development of all internet-based programmes.

Table 9: Findings, Categories and Sample Illustrations

Study	*Findings*	*Sample Illustrations*	*Categories*
Paper 1: Preconception counselling resource for women with diabetes	Lack of preparation for pregnancy Major barrier is a lack of knowledge as to the need to plan and the reasons why Urgent need to raise awareness of the importance of pregnancy planning among women with diabetes and health care professionals Empowerment of health care professionals to provide pre-pregnancy care Women with type 2 diabetes hard to reach group Majority of women were aware of the need to plan pregnancy but few aware of the rationale for planning and uncertain about what pre-pregnancy advice entailed. Urgent need for women to receive guidance about planning pregnancy in a motivating, positive and supportive manner Importance of user/patient involvement in the creation of educational resources Real lives approach - cast of women with diabetes in the resource	"This project has highlighted the importance of user/patient involvement in the creation of educational resources. Ideas and plans for the resource which the team had discussed prior to the focus groups were altered substantially once focus group feedback was considered. For example, the team had considered the inclusion of video footage of healthcare professionals within the resource advising women on planning pregnancy. Women rejected this idea, instead wanting a real lives approach which led to the resource having a 'cast' of eight women with diabetes women with diabetes during the design and development phase of both the DVD and the subsequent website development led to the creation of a highly acceptable preconception counselling resource"	KNOWLEDGE: Need for increased knowledge about importance, reasons for and what is included in, pre-pregnancy counselling – for women with type 1 diabetes and health care professionals EMPOWERMENT – for health care professionals in providing PPC EQUITY – understanding and researching how to reach hard-to-reach and vulnerable groups POSITIVE SUPPORT – pregnancy information provided in a positive, motivating and supportive manner PERSON CENTRED - it is recommended to include women's voices, stories and experiences, in the development of internet-based resources and programmes, with a participatory approach.
Paper 2: Young Women with diabetes: Using	Stability during life transitions	'I am sure there are many common problems and people	POSITIVE SUPPORT – pregnancy information provided in a positive,

Internet communication to create stability during life transitions – 2007 – *Grounded Theory*	Changing social and emotional conditions during transitions Autonomy Being in control Need for health information and social interactions Reluctance to reveal diabetes Anonymity Impact of diabetes on friends and family Responses of others to their diabetes Social support – the manner in which it is provided and how it is perceived by individuals with diabetes Discriminatory responses Safeguarding anonymity using websites and emails Forming meaningful relationships during transitions Reduced anxiety Relief Knowing others understood what they were going through Constantly changing information needs Bounce ideas off others Sensitive issues including contraception	post notes on the Reality Check Web sites, but it is good to have it, you know, for younger people, they do not want that formality.' 'Discussing difficulties does not need to be that people have to see a counsellor, it could just be, you know, walk with the net. Young people are really good with e-mails and all that kind of stuff. It could just be someone there [to discuss with].' 'Because my family is a long way away, I have to call them regularly to touch base. Fortunately, both my Mum and my sister are on the emails now, so that is good. I can e-mail them as well.' 'The Reality Check website has been great. I feel much more a part of it now. It is especially doing stuff with the support group where lots of things are going on. I didn't know about all the other people who also had diabetes. I had met a couple of people here and there, who had Type 1 diabetes, but moving down here and doing stuff with the support group was just fabulous.' 'I had some friends I have made in New York over the websites and e-mails. One of	motivating and supportive manner AUTONOMY – women can access information at a time that suits them and maintain control of their diabetes and their lives KNOWLEDGE: Need for increased knowledge about importance, reasons for and what is included in, pre-pregnancy counselling – for women with type 1 diabetes and health care professionals PERSON CENTRED - it is recommended to include women's voices, stories and experiences, in the development of internet-based resources and programmes, with a participatory approach in development of resources and internet-based support; and in-service delivery SOCIAL SUPPORT AND UNDERSTANDING – from other women with type 1 diabetes FAMILY RELATIONSHIPS – avoiding negative impacts on loved ones and/or negative responses to issues raised about diabetes and pregnancy COMMUNICATION – positive and balanced communication between HCP's and women with type 1 diabetes REDUCED ANXIETY AND DISTRESS –

	and sexual issues easier to discuss Find their way Find their feet On their own terms Sense of belonging Reassurance Update knowledge Share information about new tech Easier to access information Reduce isolation Growth in self-confidence and self-assurance Empowerment to make decisions Good communication central to patient-health professional relationships Increased vulnerability during transitions More participatory shared management role Expert patients Emotional and social support Flexible, available 24 hours a day Low cost Informal Disclose sensitive issues	them has two diabetic kids and they are both on the pump. So, I sort of started to talk to her about it. I found it interesting and I started reading about it. I decided, yes, I want that.' 'I think about things like the Reality Check website. That is what I use a lot. People post notes for everything and a lot of it is about facing discrimination or 'I fear, I panic, what do I do?' or 'What can I do in this situation? And in that situation?' And gives me reassurance about my diabetes management.' 'Reality Check website helped me to put things in their right place within my emotions, my personality. The really beautiful thing was that it allowed me to feel in control.' 'I probably sound like a lunatic, but now I know that the web sites are there, I would check that every day. There might not be anything on it, but just the fact, I don't know, it is almost like a bit of a release and quite often I put some questions up on the forum they have got and straight away, people that you know have had it for a long time, or they know what you are going through, so they will	reassurance, lowered anxiety, reduced isolation, easier to raise sensitive issues OPTIMISM AND HOPE –leading to growth in self-confidence and empowerment to make decisions ACCESSIBIILTY TO INFORMATION AND SUPPORT – flexibility in access, can be accessed anywhere at any time of the day, variety of information sources, in their own terms SELF-ESTEEM AND SEL-EFFICACY – internet-based resources allow women to determine when, where and what information and support they seek; in private and preserving anonymity

	Multiple sources of information	put in what they think and that. It is really a great outlet. That is why I think it is fantastic.'	
Paper 3: Internet use, needs and expectations of internet-based information and communication in childbearing women with type 1 diabetes	Information seeking using the internet in the childbearing years Pregnancy and early motherhood more complex situation than for women generally Need for health care professional support Need to bridge any discontinuity in care Women feel alone and vulnerable Feeling dependent on partners Participatory approach Taking into consideration users' different degrees of use and experience Reliable, up-to-date information focused on child-bearing and diabetes Expert-controlled website Improved access to HCP's Alternative ways to communicate and to receive childbearing related support Online technical devices to manage frequent BGL monitoring	'Instead of visits, it would have been convenient to be able to check with people over the phone or perhaps online, simply to verify blood sugar levels, insulin doses, and the like. Mainly during early pregnancy, when there are no other checks on the child. Also, before the pregnancy is public knowledge, people prefer not to have to go to the hospital for check-ups too often, as it makes them feel as if they are under suspicion at work, which is stressful. In other words, a way of managing and looking after women, particularly in early pregnancy, that is a little more convenient and "discreet", but naturally without imparting a sense that the quality of care is being compromised.' 'I was part of a forum for pregnant Type-I diabetics on the website "Family life" (spontaneously established). I also met some of the mothers in person, and followed up on them during their second pregnancy too. What felt so important in these contacts was that they felt better understood,	KNOWLEDGE: Need for increased knowledge about importance, reasons for and what is included in, pre-pregnancy counselling – for women with type 1 diabetes and health care professionals EMPOWERMENT – for health care professionals in providing PPC POSITIVE SUPPORT – pregnancy information provided in a positive, motivating and supportive manner PERSON CENTRED - it is recommended to include women's voices, stories and experiences, in the development of internet-based resources and programmes, with a participatory approach in development of resources and internet-based support; and in-service delivery BALANCE – balance between pregnancy risk information and becoming and being a mother AUTONOMY – women can access information at a time that suits them and maintain control of their diabetes and their lives SELF-ESTEEM AND SEL-EFFICACY – internet-based resources

	Informal, emotional and appraisal support from women in similar situations to provide an arena for belonging instead of creating feelings of alienation Reliable information Interactive support Social networking Prepare women before meetings with health care professionals Many health care professionals do not seem to use the possibility of incorporating internet information into the care of patients in general, including pregnant women. HCP lack confidence in reliable information Need for internet-based support directed towards pregnancy, childbirth and parenthood. Need for positive attitude from HCP's in order to alleviate stress and worry over baby's health due to diabetes.	and were able to hear about other people in the same situation. Pregnant diabetics go through much more than other mothers, and so it feels even more important to them to find people with whom to share experiences, ideas, and emotion'	allow women to determine when, where and what information and support they seek; in private and preserving anonymity SOCIAL SUPPORT AND UNDERSTANDING – from other women with type 1 diabetes FAMILY RELATIONSHIPS – avoiding negative impacts on loved ones and/or negative responses to issues raised about diabetes and pregnancy COMMUNICATION – positive and balanced communication between HCP's and women with type 1 diabetes REDUCED ANXIETY AND DISTRESS – reassurance, lowered anxiety, reduced isolation OPTIMISM AND HOPE –leading to growth in self-confidence and empowerment to make decisions ACCESSIBIILTY TO INFORMATION AND SUPPORT – flexibility in access, can be accessed anywhere at any time of the day, variety of information sources QUALITY OF INFORMATION – needs to be reliable information, guided by HCP experts

			EQUITY – how to reach hard-to-reach and vulnerable groups
Paper 4: Prototype for Internet support of pregnant women and mothers with type 1 diabetes: focus group testing	Loss of control, Negative feelings and insecurity related to childbirth Greater anxiety Health care lack of focus on the mother Need to share with other women with diabetes Dissatisfied with the information given by health care professionals Using Internet to seek information Access to information Ability to ask questions of experts Support **Two major themes re-evaluation**: Easily understood interface, but in need of a more blood-glucose focused orientation and forum for interaction with both equals and experts **Sub-themes** Blood glucose versus insulin Application for smart phones The time aspect Interface technology Forum	The most positive comments concerned the forum. The women considered the forum to be invaluable for coming into contact with other women in the same situation as themselves and who had the same life experience of diabetes that some health care providers lack. The forum was not solely focused on blood glucose levels, and would make a positive contribution to their network of information. ("... sure, those who work with diabetes and pregnancy know the facts of how diabetes works, but they can never understand the feelings that are involved, how you make it work in your everyday life, they can only provide tips about how others deal with it, it's easier to talk to someone who is actually in the exact same situation.")	POSITIVE SUPPORT – pregnancy information provided in a positive, motivating and supportive manner PERSON CENTRED - it is recommended to include women's voices, stories and experiences, in the development of internet-based resources and programmes, with a participatory approach in development of resources and internet-based support; and in-service delivery EQUITY – how to reach hard-to-reach and vulnerable groups SOCIAL SUPPORT AND UNDERSTANDING – from other women with type 1 diabetes COMMUNICATION – positive and balanced communication between HCP's and women with type 1 diabetes REDUCED ANXIETY AND DISTRESS – reassurance, lowered anxiety, reduced isolation, easier to raise sensitive issues ACCESSIBIILTY TO INFORMATION AND SUPPORT – flexibility in access, can be accessed anywhere at any time of the day, variety of information sources, in their own terms

	Direct link to the diabetes midwife Ask the expert Lack of contact information		BALANCE – balance between pregnancy risk information and becoming and being a mother AUTONOMY – women can access information at a time that suits them and maintain control of their diabetes and their lives UP-TO-DATE AND RELEVANT TECHNOLOGY – keeping up with changes in digital health, diabetes management tools and variability between users' skills and knowledge in using digital tech
Paper 5: Person-Centred Web Support to Women with type 1 diabetes in Pregnancy and Early Motherhood – the Development Process	Pregnancy and early motherhood extraordinarily demanding for women with type 1 diabetes Need optimal support Person-centred care Participatory design Process mapping Diabetes is unique as much of the day to day care rests with the person themselves Due to demanding requirements during the period of pregnancy and early motherhood, there is a need for extended professional care, education, and counselling regarding self-care, provided in ways that move beyond the illness of diabetes and focus on the person.	Identified need was the women's call for sharing common experiences with others in similar situations, a need that could not be met within the healthcare setting. Step 2: Evidence synthesis - evidence should be synthesized in order to provide the core content for Internet-based interventions. The identified scientific literature in Step 1 concluded that the period of pregnancy through early motherhood is challenging and demanding for women with chronic diabetes. There are increased risks for preeclampsia, malformations, fetal asphyxia, caesarean section and	EXTRAORDINARILY DEMANDING – pregnancy for women with type 1 diabetes is more demanding than usual SOCIAL SUPPORT AND UNDERSTANDING – from other women with type 1 diabetes WOMEN AS MOTHERS' – opportunities for women to engage in conversations around becoming and being a mother rather than focus on diabetes at all contacts POSITIVE SUPPORT – pregnancy information provided in a positive, motivating and supportive manner PERSON CENTRED - it is recommended to include women's voices,

	Applying a broader scope of medicine Approaching the patient as a person Developing a therapeutic alliance Accomplishing shared decision-making Expressing this in documentation Empowerment Secure transition to motherhood Strengthen self-management capabilities Autonomy Body is experienced as changed and unpredictable Pregnancy and childbirth involve extensive health care, but the mothers have experienced it as mainly focusing on foetal and neonatal health and not on their own well-being Seen as people rather than objectified as individuals with a chronic illness, including an established therapeutic alliance with healthcare professionals.	instrumental vaginal birth, perinatal mortality, and neonatal complications. The most important factor for optimizing chances of having a healthy child is maintaining maternal normoglycemia h/day during pregnancy.	stories and experiences, in the development of internet-based resources and programmes, with a participatory approach in development of resources and internet-based support; and in-service delivery COMMUNICATION – positive and balanced communication between HCP's and women with type 1 diabetes REDUCED ANXIETY AND DISTRESS – reassurance, lowered anxiety, reduced isolation, easier to raise sensitive issues ACCESSIBIILTY TO INFORMATION AND SUPPORT – flexibility in access, can be accessed anywhere at any time of the day, variety of information sources, in their own terms BALANCE – balance between pregnancy risk information and becoming and being a mother AUTONOMY – women can access information at a time that suits them and maintain control of their diabetes and their lives SHARED DECISION MAKING – between women and health care professionals UP-TO-DATE AND RELEVANT TECHNOLOGY – keeping up with changes in digital health, diabetes

			management tools and variability between users' skills and knowledge in using digital tech
Paper 6: Web-based Intervention for Women with type 1 diabetes in pregnancy and early motherhood: Critical Analysis of Adherence to Technological Elements and Study Design	Technology and study design matter and might mutually influence each other. Need for evaluation. Five design principles were used in the MODIAB-Web study: trustworthiness, expertise, surface credibility, real-world feel, and authority. Forum Content and Type of Peer Support Adherence in Relation to Study Design Adherence in Relation to Technology In Internet-based interventions, the use of design theories enables utilization of the full potential of technology and promotes adherence The randomization element in a randomized controlled trial design can become a barrier to achieving a critical mass of user interactions in Internet-based interventions, especially when social support is included For extended study periods, the technology used may need to be adapted in line with newly available	Dialogue—Example 1 Woman 1: "As a diabetic, having kids isn't a walk in the park but I've managed twice before with completely perfect kids…this pregnancy has been really tough – with high blood pressure and low sugar but after a lot of messing about, it's sorted itself out now." Woman 2: "I'm so inspired and motivated when I hear people like you – congratulations on pregnancy number three! I'm in my first but we're almost the same age and I've been a diabetic for 22 years. My biggest worry is the hypos. I hate them and I worry the baby can feel them. Once all its organs are, I'm s' and I know it can produce insulin and has a liver with a glycogen store, I'll be calmer. My levels aren't low all the time – my HBA1C is 7.9 so it has to be lowered. One side effect of my managing to lower it is that I'm more insulin sensitive. But I know that changes in different stages of pregnancy. Was it obvious in your other pregnancies – in which case, when might you	TECHNOLOGY AND STUDY DESIGN – consideration of the changing nature of technology and how study design might be impacted EXTRAORDINARILY DEMANDING – pregnancy for women with type 1 diabetes is more demanding than usual SOCIAL SUPPORT AND UNDERSTANDING – from other women with type 1 diabetes PERSON CENTRED - it is recommended to include women's voices, stories and experiences, in the development of internet-based resources and programmes, with a participatory approach in development of resources and internet-based support; and in-service delivery REDUCED ANXIETY AND DISTRESS – reassurance, lowered anxiety, reduced isolation, easier to raise sensitive issues POSITIVE SUPPORT – pregnancy information provided in a positive, motivating and supportive manner

	technical options to avoid the risk of becoming outdated in the user realm, which in turn might jeopardize study validity in terms of randomized controlled trial designs. When designing an Internet-based intervention, use existing design theories to utilize the full potential of the technology and increase adherence, especially with regard to social support. Be realistic when calculating your sample size. Take the risk of losing participants and poor adherence to the intervention into account. Be aware of limited target populations. If the number of possible participants is low, consider starting the intervention in multiple study centres simultaneously to avoid prolonged study periods and thereby outdated technology. Bear in mind that the majority of participants will not actively engage in discussions in peer support forums. Therefore, a larger critical mass of participants is needed in interventions based on effects of social support. Keep the design of the forum for peer support	have become more insulin resistant? I'm noticing I'm actually pregnant now, week 10+4, and I've done the CUB (Combined Ultrasound and Biochemistry screening) and one ultrasound. So, it's weird and wonderful to see that a fetus is living inside me. Of course, it's early yet but it feels real now. I won't tell them at work until after week 12. How do you feel about telling people, when did you do that? Woman 1: "Yes the hypos suck, I have to say but don't worry during the first weeks, during this pregnancy I had such low levels an ambulance had to come lots of times but those little ones are tough – nothing happened to him. Now I'm in week 20+. What happens when you have high levels is that the baby has to work harder to produce more insulin but at low levels, not much happens, as long as you don't go into a coma, that is – don't push yourself or you'll go mad. I told work about my first pregnancy straight away but that was because I had heavy lifting and stuff to do. I've always felt you should say when you're ready to say you're going to become a mum. And it takes time, I promise	COMMUNICATION – positive and balanced communication between HCP's and women with type 1 diabetes ACCESSIBIILTY TO INFORMATION AND SUPPORT – flexibility in access, can be accessed anywhere at any time of the day, variety of information sources, in their own terms BALANCE – balance between pregnancy risk information and becoming and being a mother AUTONOMY – women can access information at a time that suits them and maintain control of their diabetes and their lives TECHNOLOGY AND STUDY DESIGN – consider the changing nature of technology and how study design might be impacted. Keep design simple and consider integrating with existing social media. LIMITED TARGET POPULATION – be realistic when calculating your sample size. Be aware of limited target population. Design your study with multiple methods of analysis. PEER SUPPORT – consider engaging a study facilitator from your target group. A larger critical mass of participants may be

	simple and avoid divisions. Web-design is often costly if the researchers do not possess the skills themselves or team up with researchers from other fields. Consider integrating your intervention into existing social media (but be aware of ethical pitfalls if you cannot guarantee the security and confidentiality of data). If your intervention consists of a forum for peer support, consider engaging a study facilitator from the target group for the entire study period to boost activity. Health interventions are often complex in their nature. RCT design is one way of evaluating the effects of an intervention but it is in itself inadequate for truly capturing complex interactions. Design your study with multiple methods of analysis and consider the contamination of the control group as technology evolves during the study period Adjust per-protocol criteria after intended usage or conduct a dose-response analysis to properly evaluate the effect of the intervention within the RCT design.	you – I've been a mum for almost eight years now and I still can't see myself as one. Everything will be alright, you'll see. Everything's tough at the start but with time it gets better and calmer. Woman 2: "Thanks for such a good answer – it's calming what you write about having hypos." Dialogue—Example 2 Woman 3: "I wonder if there are others like me who think it feels like all the focus is on the disease/s and that you never talk about the pregnancy. I'm in week 29 and had diabetes for 22 years and I also have trouble with my thyroid. My blood sugar and thyroid tests all have great results but still the midwife just keeps talking about the diseases. Have you experienced that? Do you get enough support around pregnancy issues or is the focus only on the diabetes?"	needed to account for active vs passive users. SHARED DECISION MAKING – between women and health care professionals COST ANALYSIS - considering all potential issues in development and evaluation of internet-based programmes SECURITY AND CONFIDENTIALITY OF DATA – important consideration in development of internet-based programmes

DISCUSSION OF FINDINGS AND CATEGORIES

1) Need for Increased Knowledge

A need for increased knowledge about pregnancy and type 1 diabetes was a major finding of this meta-synthesis – for both women with type 1 diabetes and health care professionals. This related to knowledge about the importance of, and reasons for, pre-pregnancy counselling; what is included in pre-pregnancy counselling; knowledge about changes to diabetes management and what to expect during pregnancy; where to access support, and when to seek this (Sparud-Lundin et al., 2011a). Whilst other chapters of this thesis have discussed knowledge about pregnancy and pre-pregnancy counselling as being of primary importance for women with type 1 diabetes, it is of considerable note that this study specifically highlights the knowledge of health care professionals in relation to pre-pregnancy counselling, as needing addressing.

Internet-based programmes and resources are well positioned to deliver knowledge and information, and this finding suggests that one of the benefits for women with type 1 diabetes is that online resources offer flexibility in access, anonymity, and can deliver a variety of types of information (Rasmussen, Dunning, & O'Connell, 2007). Supporting arguments in other chapters of this work, this finding also recommends that a balance between pregnancy risk information and becoming and being a mother, must be incorporated in any internet-based resources and programmes (Gough, McCance, Alderdice, Harper, & Holmes, 2015). It is further recommended that this information be guided by health care professionals who are experts in pregnancy and diabetes, and women with diabetes themselves, with consideration of inclusion of women with type 1 diabetes as moderators of any forums or social media groups. Websites must include validated links with regular updates to information (Berg et al., 2018; Rasmussen et al., 2007).

2) Person-Centred Care

Person-centred care was an important finding across the meta-synthesis. Empowerment of women with type 1 diabetes through person-centred care was considered central and was presented in two ways:

1) The need to support more skills training and education for health care professionals so they can provide appropriate pre-pregnancy counselling which is inclusive of women with type 1 diabetes as active participants, particularly for those in general practice; and

2) The need to provide pregnancy information for women with type 1 diabetes in a positive, motivating and supportive manner, to increase self-efficacy and optimism. Positive and balanced communication between health care professionals and women with type 1 diabetes was considered important.

Again, these aspects are important considerations because they relate not just to the need for increased skills and knowledge for women with type 1 diabetes, but also a focus on health care professional training and resources, and changes to policy.

3) Peer, Health Care Professional and Family Support

The findings suggested that as well as information seeking, internet-based programmes and resources which include forums and social media, have the potential to reduce isolation and distress for women with type 1 diabetes during pregnancy (Sparud-Lundin et al., 2011a). Trained moderators – both health care professionals and peers - were highlighted as being important in such forums, whether on websites or social media. Using internet-based communication to share issues and concerns with peers and health care professionals enabled women to avoid negative impacts on loved ones and/or negative responses to issues raised about diabetes and pregnancy when sharing with them (Adolfsson & Jansson, 2012; Sparud-Lundin et al., 2011a).

4) Mental Health

The findings in relation to mental health suggested that internet-based programmes and resources could offer reassurance, lower anxiety, reduce isolation, and make it easier for women to raise sensitive issues such as pregnancy and contraception (Rasmussen et al., 2007). Being able to easily communicate with peers, seek relevant knowledge, and feel in control of these things, was seen as one of the major aspects of facilitating growth in self-confidence and empowerment to make decisions. Internet-based resources allowed women to determine when, where and what information and support they sought, preserving anonymity where desired (Berg et al., 2013). Finally, the use of internet-based programmes provided opportunities for women to engage in conversations around becoming and being a mother with peers, rather than simply focusing on diabetes and pregnancy risks.

5) Inclusion of Women's Voices

A finding in relation to the development of internet-based programmes and resources was that partnership between health care professionals and women with type 1 diabetes with a participatory approach in their development, is important. Women's voices, stories and experiences, should be central to the development, testing and evaluation of any internet-based programmes and resources.

In delivery and evaluation, the majority of participants will not actively engage in discussions in peer support forums, but may be gaining support through being passively involved. When designing online programmes, it is important, therefore, to ensure you have a larger critical mass of participants, to account for this fact (Berg et al., 2018).

6) Use of Appropriate Technology

In terms of the development of new internet-based programmes and resources, the findings indicated that an understanding of how to access 'hard-to-reach' and vulnerable groups using internet-based technologies, is a priority (Gough et al., 2015). Maintaining expertise with

changes in digital health, diabetes management tools and variability between users' skills and knowledge in using digital tech, was recommended as an ongoing priority (Berg et al., 2018). Understanding the changing nature of technology and how study design might be impacted when researching internet-based programmes, was also an important finding. Where there is a limited target group, such as the one used in my study two, (chapter 4), it is difficult to carry out the comparative element required for an RCT design, which creates a barrier to achieving enough user interactions (Berg et al., 2018). The nature of longer project periods means that the technology being used has to maintain current technical options that might change and/or become available during the study, which can impact study validity. However, if the technology used does not keep up with current technology, it can be seen as outdated by those who will be using the programmes and resources in real world situations (Berg et al., 2018). In particular, platforms for social media are often changing and users might move from one to the other. This was evident in study one (chapter 3) where women who had been using the forums onboard the DCO website, shifted to the Facebook group.

In relation to providing social support via internet-based programmes and resources, a further conclusion is that using theory to underpin your research and programme development process, allows you to create a technological design that incorporates multiple elements to meet a variety of user needs. However, Berg and colleagues also noted that even apparently low user activity, could still be offering social support for the individual, regardless of whether she is an active or passive user of the website (Berg et al., 2018). Some women might be actively posting within groups and forums, whereas others might seek support via reading the conversations. Still others, may come in and out of conversations as needed.

Security and confidentiality of data were flagged as important considerations in development of internet-based programmes and resources, ensuring that users' privacy and

data are protected when using the platforms. And finally, considering all potential costs and budgetary issues in development and evaluation of internet-based programmes, including ongoing costs and provision of resources such as moderators, was highlighted as important from the outset (Berg et al., 2018) .

SYNTHESIZED STATEMENTS

After extraction of the initial findings, and development of categories and synthesised findings, my primary supervisor independently read and evaluated two of the papers included in the meta-synthesis, to ascertain whether she agreed with these, as I had determined. She considered the findings and illustrations for these, mapped against the categories I had developed. There was some discussion around the category relating to 'Partnership between health care professionals and women with type 1 diabetes' – which I later adapted to relating to a participatory design approach in developing internet-based programmes and resources. It was also confirmed that the analysis of papers considered each paper in its entirety and not just the results sections. When satisfied that we had reached agreement on these, I took the final step of developing the following nine synthesised statements, which are presented here. These are considered the final outcome of the meta-synthesis and could now be used to inform those wishing to develop and/or research internet-based programmes and resources related to type 1 diabetes and pregnancy.

1. Women with type 1 diabetes can benefit from information, resources and support around pregnancy and diabetes via internet-based programmes, however, there appears to be a lack of such programmes, and a lack of research.
2. Internet-based programmes and resources enable anonymity if desired, autonomy and empowerment for women with type 1 diabetes.

3. When developing internet-based resources and programmes for type 1 diabetes and pregnancy, there is a need for a person-centred approach, including women's voices in their development and evaluation, with a participatory design approach.
4. Forums and social media groups for pregnancy and type 1 diabetes might benefit from both the inclusion of expert health care professional moderators and peer support leaders.
5. Internet-based programmes and resources around pregnancy have the potential to offer women with type 1 diabetes reassurance, lower anxiety, reduce isolation, and make it easier for them to raise sensitive issues outside of their family and usual health care teams, including pregnancy and contraception.
6. In developing internet-based pregnancy programmes and resources for women with type 1 diabetes, ongoing budget needs for changing technology and human resources should be considered; changes in digital health and diabetes management tools incorporated; and knowledge of how users might want their management devices to interact with online programmes and existing social media, considered.
7. It is important to consider variability between users' skills and knowledge in using digital technology, when setting up internet-based programmes and resources; as well as how to target hard to reach groups.
8. In evaluating internet-based programmes and resources, the changing nature of technology and how study design might be impacted by this, as well as the capacity to recruit and retain participants with limited target groups, should be considered.
9. Security and confidentiality of data are important ongoing considerations in the development and management of all internet-based programmes and resources.

STRENGTHS AND LIMITATIONS

There are a number of strengths to this meta-synthesis. I used a comprehensive literature review to source the papers analysed. I then based my inclusion of papers for the analysis on the JBI methodology for qualitative meta-synthesis, ensuring there was rigor in the process. I consulted with an expert in this methodology for advice prior to starting the research and had input from my supervision team, relating to clarification of findings as I progressed through the analysis.

In terms of limitations, the study literature review protocol was not pre-registered on any relevant databases, and whilst rigorous, was not a systematic review. Due to time constraints, only two researchers independently considered the findings and category development, which is less than generally recommended. There were only a small number of studies and, therefore, the synthesis is based on 6 papers (3 studies.) However, this is in itself an important observation, in that there is a large gap in the current body of literature in relation to the use of internet-based programmes and resources for pregnancy and type 1 diabetes. One of the recommendations of this study, is that more work is performed in this area, including some demonstration that an online source offering good info and support actually contributes to more positive outcomes.

IMPLICATIONS FOR PRACTICE

An online survey of 664 mums-to-be (not diabetes specific) in September 2011, using online survey software across popular parenting websites www.kidspot.com.au and www.birth.com.au found that both pregnancy focused websites and email newsletters are the most significant resource for all pregnant women, with 72% visiting sites weekly and 58% visiting sites daily (Ross, 2011). People with diabetes regularly access popular online social networking sites and report that they are willing to discuss health information online (Shaw & Johnson, 2011). With over 17,000,000 Monthly Active Australian Users on Facebook alone

as at April 2017, popular online social networks and online social media have the potential to serve as important platforms for interventions in type 1 diabetes and pregnancy, and to reach diverse populations ("Social Media Statistics Australia April 2017," 2017).

The Sensis Social Media Report 2017 ("Sensis Social Media Report," 2017) shows that social media usage is now almost universal among 18-29-year old's in Australia (99%), with substantial increases in use in the 30-39 age group since 2016 (up 14 points to 96%) and the 40-49 age group (up 16 points to 86%). Another factor in the argument for development of internet-based programmes and resources for pregnancy and type 1 diabetes is the increase in smartphone ownership, with 81% of Australians now preferring to use their mobile device to access social media, as opposed to a laptop (30%) or desktop (28%) therefore making information accessible while individuals are mobile ("Sensis Social Media Report," 2017).

This small meta-synthesis has shown, however, that despite all of this evidence showing usage of the Internet, there are currently few studies which have examined the use of the Internet, mobile Apps, web-based or social media programmes and resources, specifically to support women with type 1 diabetes during the pregnancy journey.

During the literature search, I was only able to find 13 papers initially, which was reduced to 6 papers (3 studies) that were of a qualitative nature, on this topic. More studies examining how to use the Internet and mobile apps to reduce the risk of type 2 diabetes for women with gestational diabetes following pregnancy, were discovered, than those pertaining to type 1 diabetes. In addition, a small number of quantitative studies specific to type 1 diabetes were found, but these were not included in this qualitative meta-synthesis. Given the number of women in general using the Internet for pregnancy information and support, and the thriving diabetes online community, it is clear that further work in this area is needed.

During the meta-synthesis, it was revealed that relationships are the central component to internet-based programmes, offering women a place to connect with others who understand

(Sparud-Lundin et al., 2011a) . Seeking such advice online removes the pressure some women might feel their family members would experience, or potentially negative reactions to their desires to become pregnant (Adolfsson & Jansson, 2012). In the papers analysed, using internet-based communication to share issues and concerns with peers and health care professionals enabled women to avoid negative impacts on loved ones and/or negative responses to issues raised about diabetes and pregnancy (Sparud-Lundin et al., 2011a). Using internet-based programmes offered opportunities for women to engage in conversations around becoming and being a mother, rather than simply focusing on diabetes and pregnancy risks and management, which in turn promotes the potential for a positive pregnancy journey (Sparud-Lundin et al., 2011a).

It is suggested, through the analysis in this meta-synthesis, that there is a need for increased knowledge around pre-pregnancy counselling - for both women with type 1 diabetes and health care professionals (Gough et al., 2015). A balance between pregnancy risk information and stories about becoming and being a mother, is recommended in any internet-based resources and programmes. There should be reliable information, guided by health care professional experts and women with type 1 diabetes, with validated links and updates to information (Gough et al., 2015). As with any other care, internet-based programmes should be person-centred, including women's voices in their development and evaluation (Gough et al., 2015; Sparud-Lundin et al., 2011a).

CHAPTER 6: OVERALL DISCUSSION AND CONCLUSIONS

This PhD research was underpinned by evidence that type 1 diabetes is one of the most common conditions complicating pregnancy; that women with type 1 diabetes experience much higher than usual adverse pregnancy outcomes; and that despite advances in the management of type 1 diabetes, these risks persist. During my initial literature review, it was clear there were substantial gaps in relation to women with type 1 diabetes' experiences of pregnancy. There was also a lack of research examining diabetes related distress and psychological wellbeing for women with type 1 diabetes during pregnancy; a lack of consistent knowledge about how health care professionals might improve pre-pregnancy services and uptake of pre-pregnancy counselling; and how they might provide better support during the pregnancy journey, particularly via internet-based resources and programmes.

The overarching purpose of this thesis, therefore, was to:

1) Better understand the experiences of pregnancy for women with type 1 diabetes, highlighting the time phases of this journey and the key issues arising during each time phase;

2) Develop a prototype communication support Questionnaire for use during contemplation of pregnancy, to open up conversations about pregnancy and pre-pregnancy counselling, which might enhance this journey; and

3) Examine the qualitative literature in relation to the use of internet-based programmes and resources in delivering pregnancy information and support for women with type 1 diabetes, to highlight gaps and opportunities for further work.

This chapter will summarise and amalgamate the findings of the three studies, followed by discussion of the overall findings, how I have answered the research questions and addressed the aims, and the contribution to knowledge. Finally, I will highlight the recommendations for future work and the key points I would like the reader to take away.

STUDY 1: UNDERSTANDING THE JOURNEY OF PREGNANCY FOR WOMEN WITH TYPE 1 DIABETES

The first study presented in this thesis (Chapter 3) explored the journey of pregnancy for women with type 1 diabetes, via a thematic analysis of online diabetes counselling records. A number of questions were developed prior to undertaking the analysis, based on the initial literature review at the outset of the work:

- What are the issues women with type 1 diabetes bring to the DCO website around pregnancy and early motherhood?
- What prior experiences do they have with health care professionals in relation to pregnancy information and support? How useful has this been and where are the gaps in relation to pregnancy information and support?
- How have family, friends and peers been involved in women's prior experiences of pregnancy information seeking, and/or during pregnancy?
- Are women with type 1 diabetes attending pre-pregnancy counselling, and at what point? Are they seeking information from other sources and if so, what are they?
- Is diabetes specific distress present during the pregnancy journey, and if so, what is the nature of this at various time points and how is this identified?
- Do women experience depression at any stage of the pregnancy journey and how is this identified?

As this was an analysis of written counselling records and social media conversations, I was in the unique position of being able to examine women's experiences from when they were just considering pregnancy at some time in the future, through to motherhood. The women were approaching this service voluntarily for support. The thematic analysis was, therefore, carried out on the women's words verbatim, as there were digital records. The analysis resulted in the development of a theoretically driven model of the pregnancy

journey, which provided insight into many of the issues raised via the research questions, across the time-phases of this journey, highlighting the key experiences and issues women with type 1 diabetes might face at each point.

Whilst it was revealed that the phases of the journey of pregnancy were essentially the same as any other woman's – that being pre-pregnancy, the 3-trimesters of pregnancy, birth and motherhood (with a small number who experienced pregnancy loss), there were specific aspects to that journey that made it unique, and which contribute to current knowledge. This includes the fact that the Contemplation period of pregnancy is very important for women with type 1 diabetes and may last for many years. This period of Contemplation is the point at which information about the impact pre-pregnancy counselling can have on the potential for a healthy pregnancy, could be introduced, rather than waiting until a woman approaches a health care professional to begin planning for a pregnancy. This is also an opportune point at which women could be directed to seek such information themselves, via internet-based programmes and resources, where they could also make connections with peers, which have been shown to be of vital importance for some women.

The higher than usual level of medicalisation of the pregnancy experience discussed by women in the analysis, as well as the psychological impacts, also offers contribution to knowledge. Women included in the analysis shared the fact that they were required to plan their pregnancy much earlier than usual, and to seek much more intensive input from health care professionals prior to trying to conceive, than women without type 1 diabetes. For some women this led to increased anxiety about their capacity to manage their diabetes, pressure on their relationships with others, and concern about their potential to have a healthy baby. These aspects were all supported by the prior literature review.

This study also provided a unique insight into conversations about pregnancy between women with type 1 diabetes on social media, where previous research is very limited. I have presented evidence to suggest internet-based resources and programmes can engage and involve people in their own health care, and that due to the increasing accessibility of the Internet and the availability of health information online, people can now much more easily seek and find information about their health - thus, the Internet can empower people particularly in conditions such as diabetes, where intensive self-management is central (Shaw & Johnson, 2011).

The findings from study one indicated that the provision of resources for women with type 1 diabetes who are contemplating or planning pregnancy, need to balance pregnancy risk information with accounts of positive experiences of pregnancy and motherhood from other women with type 1 diabetes, and signposting to sources of peer support. It certainly cannot be presumed that if women are not attending formal pre-pregnancy counselling, that they are *not* seeking pregnancy information in planning pregnancy elsewhere. The study concluded that interventions which acknowledge women's expertise in their own type 1 diabetes; include assessment and support for mental health and wellbeing, alongside physical health; and ensure adequate social supports are in place for the pregnancy journey, are more likely to result in positive outcomes.

It is important to acknowledge that notwithstanding the large sample for a qualitative study in women with type 1 diabetes, this thematic analysis is based upon the online conversations of a somewhat select sample – that is, women seeking help via online sources, outside the normal private and public health care provision for diabetes and pregnancy. Although this study has the strength of identifying issues arising for women who may not be attending (or receiving the support they need from) traditional health care services, it is not recommended to extrapolate these findings to all women with type 1

diabetes. Given that the data were derived from naturalistic interactions with the DCO service, rather than via traditional research recruitment, we also know little about demographic/clinical characteristics (e.g. age, diabetes duration, treatment regime, pregnancy history and culture).

STUDY 2: CONTEMPLATING PREGNANCY IN DIABETES COMMUNICATION SUPPORT QUESTIONNAIRE

The findings in study one led to my decision to focus in study two (Chapter 4) on seeking ways to increase preparedness for pregnancy, as early as the Contemplation of phase of pregnancy for women with type 1 diabetes. Communication between health care professionals and women was highlighted in study one, as a pivotal theme affecting attendance at pre-pregnancy counselling. Therefore, I wanted to identify a tool that would enable positive, balanced communication between health care professionals and women with type 1 diabetes, in relation to pregnancy preparation. The primary aim was to use the model of the journey of pregnancy and key themes presented in study one, to develop a Questionnaire to support communication about pregnancy for women with type 1 diabetes during the Contemplation phase. A secondary aim was to identify and refine potential problems in the Questionnaire items, through a pilot survey.

I was unable to find an existing pregnancy specific tool that targets pregnancy preparation in type 1 diabetes. Therefore, in study two, I developed and then evaluated, the prototype Contemplating Pregnancy in Diabetes Communication Support Questionnaire. I used a theoretically driven method to develop the framework for the Questionnaire, created the items and scales, and ran a small pilot. Following the pilot, I carried out basic psychometric testing and cognitive interviews. The cognitive interviews, whilst small in number, offered insight into the face and content validity. As per the recommendations in the literature around relevance of pregnancy information, I added an item that asks firstly whether a

woman is considering having a baby in the next 1 -5 years, before proceeding. The Questionnaire is then built on the thematic analysis of study one and the literature, including items about both the desirable health behaviours for pregnancy with type 1 diabetes recommended by ADIPS and ADS; and the personal, social and psychological resources needed for the journey ("ADIPS Consensus Guidelines for the Testing and Diagnosis of Hyperglycaemia in Pregnancy in Australia and New Zealand | Australian Clinical Practice Guidelines," 2015).

This Questionnaire is now ready for wider testing in a larger and more diverse group of women, as suggested in chapter 4. Once tested, it could be used in a wide range of settings, including via online resources, such as the Australian NDSS pregnancy and diabetes website. It is recommended that in order to consider the wider applicability of the Questionnaire, further testing should include recruitment of women across a greater diversity of culture, language and socio-economic status, as well as consideration of inclusion of both type 1 and type 2, diabetes.

STUDY 3: META-SYNTHESIS OF THE QUALITATIVE LITERATURE REGARDING INTERNET-BASED, PROGRAMMES AND RESOURCES

As study one revolved around analysis of internet-based services and the themes raised in study two included the importance of both communication and wider availability of pregnancy information, I made the decision in study three to analyse the current literature with a qualitative meta-synthesis, considering the use of internet-based programmes and resources for type 1 diabetes and pregnancy. The outcomes of the meta-synthesis had clear implications for practice, including the overall finding that women with type 1 diabetes can benefit from information, resources and support around pregnancy and diabetes offered via internet-based programmes, but that there appears to be a lack of such programmes, and a lack of research.

The meta-synthesis indicated that internet-based programmes and resources enable autonomy and empowerment for women with type 1 diabetes, while preserving anonymity if desired (Rasmussen et al., 2007). When developing internet-based resources and programmes for type 1 diabetes and pregnancy, it was recommended that the approach be person-centred, including women's voices in their development and evaluation, and that any forums and social media groups for pregnancy and type 1 diabetes might also benefit from the inclusion of expert health care professional moderation, as well as peer support and moderation (Berg et al., 2018). Internet-based programmes around pregnancy have the potential to offer women with type 1 diabetes reassurance, lead to lower anxiety, reduce isolation, and make it easier for them to raise sensitive issues outside of their family and usual health care teams, including issues related to pregnancy and contraception (Adolfsson & Jansson, 2012; Rasmussen et al., 2007; Sparud-Lundin et al., 2011a). However, the magnitude of such benefits needs to be evaluated further.

Whilst the overall costs can be lower, it was recommended that ongoing budget needs for rapidly changing technology and human resources need to be considered. This might include the need for moderators of online forums and social media groups. It was also suggested that keeping up with changes in digital health and diabetes management tools, and how users might want their management devices to interact with online programmes and existing social media, would be important. Finally, any online programmes should consider the variability between users' skills and knowledge in using digital technology and the issues pertaining to small target groups and how to address this in study design (Berg et al., 2018).

STRENGTHS AND CONTRIBUTION TO KNOWLEDGE

There are a number of strengths in this work. It is important to be realistic when calculating sample size and be aware of limited target populations related to type 1 diabetes

and pregnancy. Studies around type 1 diabetes and pregnancy are often quite small in numbers as a result, particularly those of a qualitative nature (Berg et al., 2018). However, study one of this work contained 93 women's counselling records, which is one of the largest studies in the literature of a qualitative nature. This study was also able to capture the Contemplation phase of the pregnancy journey, as women were approaching the service for counselling voluntarily. This is usually difficult to achieve, because it is hard to capture a woman's intention, or thoughts about becoming pregnant, unless she actively approaches a health care professional to discuss these. Some women in this study were approaching the online service when they were in a stage of their lives where they were simply contemplating pregnancy at some time in the future. This adds a unique phase of the pregnancy journey to the current body of knowledge, and the prototype Questionnaire developed in study two, offers a unique way to address the needs for information and support about pregnancy and pregnancy planning.

There is a clear gap in the literature in relation to psychological experiences of pregnancy for women with type 1 diabetes. This contrasts with the numerous papers focusing on the medical impacts of type 1 diabetes and pregnancy, which take quantitative approaches. Many others focus on gestational diabetes. My work contributes qualitative data to the literature, in relation to women's experiences of the pregnancy journey. Notwithstanding the need for further work considering diversity, the model that was developed could now be used by health care professionals to consider the main issues women might be experiencing at each stage of the pregnancy journey, and therefore, where interventions may best be targeted.

In study two I followed a theoretically driven model for questionnaire development to ensure rigor. I used an expert panel to reduce the initial item pool, followed by a pilot with women with type 1 diabetes. Whilst small, the pilot showed promising results as to face and

content validity. It is important to note that in this particular study I was as much interested in the relevance of items to women with type 1 diabetes, as to the reliability of items. For example, where an item was consistent in its rating of 'very important' this is considered a very relevant item to women with type 1 diabetes and, therefore, useful for inclusion as a conversation starter within the context of a communication support questionnaire. If this were a tool more focused on measuring ranges of outcomes, items which consistently scored on exactly the same response for all participants, might be considered as less relevant, as it might not add any useful information.

The development of the Questionnaire was congruent with the current literature and recommendations for management of pregnancy for women with type 1 diabetes. Once more widely tested for reliability, it could provide a potential way for health care professionals to begin regular discussions about pregnancy preparation with women with type 1 diabetes, and could potentially be adapted for use in a variety of settings and types of diabetes. It could be available as a printed version and online via a website and/or mobile App.

Finally, in study three, the meta-synthesis indicates that whilst internet-based programmes and resources for pregnancy are helpful, and that women with type 1 diabetes are seeking these online pregnancy resources, there is a distinct lack of information and research. Study three also offered insights into the important considerations when developing internet-based programmes and resources. I concluded, therefore, that this is an important area for future research.

PROBLEMS ENCOUNTERED AND LIMITATIONS

There were a number of problems encountered during this work. In the first study, notwithstanding the larger numbers of women, they were potentially tech-savvy as they were voluntarily reaching out for assistance via an internet-based service, meaning they

were also more likely to be engaged in the ideas of preparation for pregnancy and management of their diabetes. There was also a lack of diversity and as it was a naturalistic study, I could not ascertain information such as demographics and culture. I cannot be certain therefore, that these women are representative of the larger pool of women who might benefit from online diabetes and pregnancy services.

In study two, due to the fact that the numbers of women with type 1 diabetes in Australia who fitted the inclusion criteria for the pilot were small; and that this is already a small target group, it was not feasible to recruit sufficient participants to test the Questionnaire fully for reliability. Therefore, I was not able to present full reliability testing of the Questionnaire as part of this PhD. The analysis should be regarded as preliminary only and the Questionnaire considered as a prototype. Again, there was a lack of diversity in relation to language and culture.

In the final study, there were only a very small number of papers discovered in the literature review. Overall, I had to continually step back from my own experiences of type 1 diabetes and pregnancy. I also had to acknowledge the impact of my role in the online diabetes community, in the responses of participants in the pilot of study two. I was able to successfully do this to a large degree, through supervision and revisiting my work to measure the findings against my personal perspectives.

CONCLUSIONS

I have presented evidence in this thesis that despite the relatively small number of women with type 1 diabetes in Australia, the risks are major, and the resultant personal and health-care costs, substantial. Importantly, this is a current priority for the Australian health system, with the Australian National Diabetes Strategy 2016-2020 (Australian National Diabetes Strategy 2016-2020) having as one of its major goals, to reduce the impact of pre-existing and gestational diabetes in pregnancy. Establishing and developing relevant and

accessible programmes for all women with type 1 diabetes is, therefore, an important part of ongoing diabetes service development in Australia. This includes the need for wider access to pre-pregnancy counselling services, both via clinics and internet-based programmes and resources (Morrison et al., 2018).

Overall, it is important to take away from this work that whilst some women with type 1 diabetes might be aware of the potential risks related to pregnancy, they may not be aware that specialised pre-pregnancy counselling services exist; they may not be offered these services; or may have other barriers, such as living in an area where specialised services are not available; being of a younger age; being from a non-English speaking background; or from a lower socio-economic background.

One of the greatest challenges for diabetes health care professionals is making person-centred care work in practice, truly engaging all people with diabetes in shared decision making (Murphy, 2012).

Certainly for women with type 1 diabetes, in relation to pregnancy, there can be a focus on measuring and recording biomedical outcomes, rather than focusing on listening to the health outcomes that people with diabetes find important, with genuine compassion and understanding (Murphy, 2012).

It is hoped that the work carried out in this thesis will contribute significantly to the literature and to the development of services which address some of the issues raised. There are a number of areas for further research which have arisen from this work, that could assist in making pregnancy information and services more equitable and accessible for women with type 1 diabetes and I will finally highlight these key themes.

RECOMMENDATIONS ARISING FROM MY RESEARCH

I have developed a number of key recommendations based on the results and findings of the three studies undertaken in this thesis. I have taken these findings and amalgamated them with gaps and issues that have arisen for me during my work. These summarise the key issues for consideration in future research, which were based on the strengths and limitations of my work, the gaps in literature and my results and observations.

1) Diversity, Type 1 Diabetes and Pregnancy

A major limitation of the work carried out in this thesis is that it does not specifically consider diversity; including culture, language, sexuality, and disability, in the context of pregnancy and type 1 diabetes. This is very important to note, in relation to the findings and in recommending further work. The majority of women included across all three studies were living in Australia, were in heterosexual relationships, were Caucasian, and English-speaking. Therefore, the results cannot be extrapolated to all women with type 1 diabetes.

In particular, with much higher rates of diabetes in Indigenous populations in Australia, this needs to be examined. Whilst the majority of Aboriginal women in Australia with diabetes during pregnancy have either type 2 diabetes or GDM, in 2016, the incidence rate of type 1 diabetes was relatively similar among Aboriginal and Torres Strait Islander people and non-Indigenous Australians, across all socioeconomic groups and remoteness areas (AIHW, 2016). It has been shown that Aboriginal Australian women with diabetes are more negatively impacted by the presence of diabetes during pregnancy, than Caucasian women (Porter, Skinner, & Ellis, 2011). A systematic review of diabetes in pregnancy, determining prevalence and impact on maternal and child health outcomes for Indigenous and Aboriginal women internationally (Porter, Skinner, & Ellis, 2012) found that diabetes prevalence in 65% of studies was greater for Indigenous and Aboriginal women than the comparison groups; Pacific Islander 8.1%, Canadian Aboriginal 11.5%, American Indian 7.9%, Australian

Aboriginal 8.4% compared with 2–5% worldwide. Of studies reporting high birth weight (>4000 g) and diabetes in pregnancy, 75% had a higher than expected prevalence, 86% had higher macrosomia prevalence and 63% had higher stillbirth rates. Aboriginal women show a substantial increase in birth weight for GDM, rates of emergency C-section and extremely high stillbirth rates (22/1000 births GDM and 53/1000 births pre-existing diabetes). This still birth weight compares to some of the highest stillbirth rates worldwide, with poor developing countries ranging from 25 to 35/1000 births in southern Africa and Asia (Porter et al., 2011).

A study in Western Australia (Porter et al., 2011) suggests that it is possible that these differences are related to inequitable services being provided to Aboriginal women – in the main, Aboriginal women with diabetes not being offered the same level of medical support and care during pregnancy and during delivery, as Caucasian women (Porter et al., 2011). It is recommended that correcting the health disparity for Indigenous and Aboriginal women with diabetes in pregnancy is a health priority (Porter et al., 2012).

Whilst not all interventions will be relevant to all women, given the diversity of the Australian population and the work being carried out in other countries in relation to type 1 diabetes and pregnancy cited in this thesis, the model of the pregnancy journey developed in chapter 3, the Questionnaire developed in chapter 4, as well as the recommendations in chapter 5 for the potential for internet-based resources and programmes, should be examined within a broader cultural context and consider a wider diversity of women.

2) Access to Pregnancy and Diabetes Knowledge

It was revealed in study one that for women with type 1 diabetes, the pregnancy journey may start well before approaching a health care professional for support; and that this might begin with seeking information about pregnancy in alternative places to usual health care services, such as online and via social media. This means that the period of Contemplation potentially might last for a number of years and be centred around knowledge seeking. In

study one, women with type 1 diabetes were seeking up-to-date knowledge about diabetes and pregnancy. This was not freely available and they sought this online because it was easier for them to do so. They were able to remain anonymous and it fitted within time constraints. In addition, they were able to access peer and health care support in the one place. Some women were scared about the unknown when it came to trying for a baby. Some reported having been given good information about diabetes and pregnancy in the past. Others had never been given any information about diabetes and pregnancy in the past, or the information they had been given about diabetes and pregnancy had frightened them. Some had difficulties accessing health care professionals who could help with managing pregnancy and they were unsure about who needed to be on their health care team when planning a pregnancy.

If some women with type 1 diabetes are seeking pre-pregnancy information and support via online sources during Contemplation, it could, therefore, be beneficial for health care professionals and diabetes services to provide more pregnancy information via internet-based programmes and resources, particularly focused on the importance of earlier than usual pregnancy preparation; availability of pre-pregnancy counselling services; and exactly what pre-pregnancy counselling entails.

Study three showed that providing pre-pregnancy information via digital means offers women with type 1 diabetes opportunities to seek information and support when they are ready, which has the potential to increase self-efficacy, and expose a wider range of women to pre-pregnancy information. Women's usual health care professionals are best positioned to direct them to such resources during discussions about pregnancy preparation.

Women's access to updated and evidence-based information about pregnancy and the importance and availability of pre-pregnancy counselling, have been identified as gaps in this thesis. It is important to explore how this can best be offered, with the Internet

potentially being an excellent way to do this, in particular via websites focusing on diabetes and pregnancy, and use of social media. These resources have the added benefit of being able to offer peer and health care professional support together and to integrate with technologies such as continuous blood glucose monitors.

3) Training and Support for Health Care Professionals

The literature review also showed that health care professionals working with women with type 1 diabetes, including general practitioners, diabetes specialists and midwifes, might benefit from more knowledge about the importance of pre-pregnancy counselling for women with type 1 diabetes and what this entails (Berg & Sparud-Lundin, 2009; Dalfra et al., 2012; King & Wellard, 2009). Recommendations from prior studies include building in systems and processes within diabetes care, to support the delivery of pregnancy planning information and raise the issue of the importance of early pregnancy preparation (Lavender et al., 2010). More resources for health care professionals as well as education about pre-pregnancy counselling, are recommended.

The nature of prior communication about pregnancy between health care professionals and women with type 1 diabetes was also shown across a number of studies in the literature, as affecting the likelihood of women attending pre-pregnancy counselling – with information about the adverse risks alone, being more likely to discourage attendance. This suggests that some health-care professionals might benefit from training in communication skills and person-centred care, with awareness raising in regards the appropriate way to approach communication about pregnancy with women with type 1 diabetes. As with the Questionnaire developed in study two, asking women if they might consider having a baby at some point in the future, and then directing them to appropriate internet-based resources and peer support which contain a balance between risks and positive stories, has the potential to encourage person-centred care and positive outcomes.

4) Personal, Social and Psychological Resources for the Pregnancy Journey

Relationships, support, and mental health, were all important themes revealed during my 3 studies and these are supported by the literature. Considering that the experience of diabetes specific distress throughout the pregnancy journey might be different to at other times in women's lives, was a major finding of the thematic analysis in study one. The body of qualitative work discussed in the literature review, shows that that whilst women with type 1 diabetes may expect more intensive medical intervention during pregnancy, and can experience reassurance from this, the intense focus on diabetes management alone both prior to and during pregnancy, can detract from the experience of being a 'mother-to-be' and increase distress and anxiety (Sparud-Lundin & Berg, 2011).

In Contemplation of pregnancy, women in study one who were approaching the internet-based diabetes counselling services, were often working on their knowledge building about diabetes and pregnancy, resolving mental health issues in readiness, and seeking appropriate health care professionals for their future pregnancy journey. Some were seeking to resolve issues with current health care professional relationships. Others felt they understood their diabetes better than anybody else, but this was not acknowledged by their health care professionals. Positive experiences included receiving affirming feedback from health care professionals. Therefore, information resources, websites and discussions about pregnancy and diabetes, need to include the impacts of pregnancy on diabetes and vice versa, desirable health-related behaviours for the pregnancy journey, in particular during pregnancy planning, and importantly, the psychosocial impacts.

In study two, these aspects were built into the Questionnaire, ensuring that women felt acknowledged and supported. The second half of the Questionnaire specifically addresses the personal, social and psychological resources available to the woman. However, feedback during the evaluation in study two revealed that women might feel less likely to

answer honestly if the Questionnaire was given to them by a health care professional, with whom they did not have a positive, trusting relationship. Therefore, building these positive relationships across the child-bearing years, is vital.

Across the time I have carried out this PhD, whilst I have shown that there is evidence in the literature and from my own studies, for negative impacts on the wellbeing of women with type 1 diabetes during pregnancy, there remains limited information about the nature and course of diabetes specific distress during pregnancy. There is a lack of research considering whether diabetes specific distress has unique aspects and/or changes across the pregnancy journey and whether levels of distress are connected to increased risks of post-natal depression. Pregnancy specific and diabetes specific measures have not been used in the available prior studies to consider distress, anxiety and depression, and this requires further work, including studies which incorporate diabetes specific distress measures such as the PAID scale to analyse the nature and course of diabetes specific distress across the pregnancy journey (Fisher et al., 2008; Polonsky et al., 1995; Polonsky et al., 2005).

Evidence from the literature reviews across this thesis, indicates that support, in particular from a woman's partner and mother, may be substantially important to positive pregnancy outcomes for some women with type 1 diabetes (Stenhouse & Letherby, 2011). However, there is little current research in relation to the experiences of partner and family, and the ways these relationships may positively or negatively impact on the experiences of women with type 1 diabetes and their ability to manage pregnancy. Women in same sex partnerships and single mothers, are also not prominent in the current research. Aspects of culture would also impact on these support systems greatly, with variation in family make-up and their roles in women's lives, being affected by culture.

5) Person-centred care and personalised medicine

The emerging field of personalised medicine (PM), sometimes called precision or individualised medicine, offers a new model for clinical practice, and when combined with internet-based programmes and resources, has the potential to offer flexible, individualised care (Perna, Grassi, Caldirola, & Nemeroff, 2017). PM suggests that clinical decisions should be based upon a person's individual profile, and that treatment should be tailored to their particular characteristics, needs, and preferences, during all phases of care - including prevention, diagnosis, treatment, and follow-up (Perna et al., 2017). In some fields of medicine, particularly oncology, PM tools have already been developed and are now part of current clinical practice, with reportedly considerable improvements in treatment outcomes (Perna et al., 2017). Real-time data collection through smart wearable devices, are also offering more opportunities to create PM approaches (Perna et al., 2017). Leading on from the prior point about the importance of addressing psychosocial issues in relation to pregnancy and type 1 diabetes, it has been recommended in a PM approach, to personalise both the psychosocial aspects of care, as well as the biological aspects, placing the person at the centre (Horne, 2017). When combined, advances in genomics, data-analytics and e-health technologies, provide the potential for PM that is 'predictive, pre-emptive, personalised and participatory' (Horne, 2017).

PM fits with the goal of person-centred care - to offer care that 'fits with the values, needs and preferences of the person, in a way that enables them to contribute input and participate actively in decisions about their health and the services they receive' (Epstein et al., 2005). People living with diabetes reportedly use a number of different strategies to create stability in their lives and improve their wellbeing, and at times like pregnancy, where there are changing social and emotional conditions, there is an enormous impact on their diabetes (Rasmussen et al., 2007). In study one of this thesis, women wrote in their emails to the

diabetes counselling services, that they experienced a struggle to balance diabetes self-management against other aspects of life, such as work, family and social life, in *all* phases of their pregnancy. The priority they placed on their diabetes self-management varied substantially across the journey. Therefore, interventions in relation to pre-pregnancy counselling are recommended to be sensitive to women's competing needs and priorities, and be flexible and widely available. Increased access to pre-pregnancy counselling is also recommended, especially in hard-to-reach groups such as rural regions, younger women, indigenous women, those from NESB and lower socio-economic groups (Murphy, 2010; Murphy et al., 2010a; Murphy et al., 2010b).

6) Internet-based Programmes and Resources

When I founded the DCO services in 2001, there were no other online diabetes counselling services in Australia, and as far as I could establish at the time, internationally. In Australia at that time, I was able to find just 3 other general online counselling services. Since then, development in the field of eHealth and related services has been rapid, and it is predicted this will continue to affect our current health care systems in a variety of ways (Ekman, 2018). In particular, technological developments for healthcare delivery have created an increase in expectations that they will provide significant efficiency gains and reductions in overall health spending (Ekman, 2018).

As an indication of this, cost data for two care models – traditional and eHealth - were collected and analysed to obtain a measure in local currency per care contact in Sweden (Ekman, 2018). The comparison showed that the total economic cost of a digital consultation is 1960 Swedish krona (SEK) (SEK100 = US$11.29; February 2017) compared with SEK3348 for a traditional consultation at a health care clinic. Cost differences arose on both the provider side and on the user side (Ekman, 2018).

E-health technologies have specific efficiencies and advantages across health promotion, prevention, early intervention and prolonged treatment (Christensen & Hickie, 2010). In relation to pregnancy and type 1 diabetes however, there is very little research to suggest exactly how much these gains might be. A suggested model for e-health that might be relevant in pregnancy and type 1 diabetes, is one where comprehensive services are placed on an internet platform and offered through free open access to a "one-stop shop" or e-health portal (Christensen & Hickie, 2010). This type of open access offers opportunity for self-help, but also importantly provides users with a sense of control over their own health and their use of health services (Christensen & Hickie, 2010). These features have been suggested as being a 'new tier of a more comprehensive and consolidated health system' and fit with the evidence presented in this thesis, recommending that women with type 1 diabetes be at the centre of their diabetes and pregnancy management; and that they can control when and where they seek information and services.

Internet-based programmes and resources have the potential to reach some of the more vulnerable groups who are reported to have barriers to accessing pre-pregnancy counselling, and to offer more individualised and person-centred care. It is suggested that when combined with useful information, timely feedback, peer support and appropriate social marketing, e-health portals (and related applications) have the potential to encourage help seeking in ways that conventional health services are unlikely to be able to replicate (Christensen & Hickie, 2010).

The provision of e-health portal services is not supposed to compete with or decrease the current level of face-to-face interactions. In fact, it is suggested that for many people, it will simply be the first step towards access to more traditional in-person health care services (Christensen & Hickie, 2010). It is predicted that the digital health care model will most likely increase both in scale and scope over the coming years (Ekman, 2018). More people

will be able to connect with a digital health care provider, and more types of services, including specialized care, will be available within such a model of care (Ekman, 2018).

As an Australian example of the cost benefits, using national guidelines, a framework was developed outlining dietitian-delivered weight management for in-person and eHealth delivery modes in Australia (Rollo et al., 2018). This framework mapped one-on-one patient–dietitian consultations for an adult requiring active management (BMI ≥ 30 kg/m2) over a one-year period using both delivery modes. The resources that were needed for both the dietitian and patient to implement each treatment mode were identified, with costs attributed for material, fixed, travel and personnel components. The resource costs were categorised as either establishment or recurring costs associated with the treatment of one patient. The results showed that establishment costs were higher for eHealth compared to in-person costs ($1394.21 vs $90.05). However, excluding establishment costs, the total (combined dietitian and patient) cost for one patient receiving best-practice weight management for 12 months was $560.59 for in-person delivery, compared to $389.78 for eHealth delivery. Compared to the eHealth mode, a higher proportion of the overall recurring delivery costs was attributed to the patient for the in-person mode (46.4% and 33.9%, respectively) (Rollo et al., 2018).

Therefore, as demonstrated, whilst in some cases, there could be higher costs in the establishment phases, once operational, there is evidence to suggest that e-health services can save on the cost of service delivery. The meta-synthesis in study three showed that to encourage positive conversations and relationships between health care professionals and women with type 1 diabetes, and allow women to be in control of seeking information and support around pregnancy, internet-based programmes and resources might be an important addition to diabetes and pregnancy services – but these need to be developed more widely and properly evaluated across a range of types of diabetes, cultural groups and

demographics; and include cost benefits. It is important to remember that the meta-synthesis in study three showed that women with type 1 diabetes should also be involved in the development and delivery of any internet-based programmes and services. Further work is recommended in this area, including examination of the barriers and levels of access to internet-based programmes and resources across various cultural groups, locations, and socio-economic groups; similarities and differences between women with type 1, type 2, and gestational diabetes, in using the Internet for pregnancy information and support; cost benefits; the integration of peer-based social media groups with health care professional support and information resources; and how useful internet-based resources are at each time-phase of the pregnancy journey.

7) Peer Support Programmes

In addition, this work has shown that women with type 1 diabetes seek support from peers during a variety of important transition times, including pregnancy and motherhood (Rasmussen et al., 2007), but this is not well understood in terms of how peers influence and impact each other in relation to pregnancy and type 1 diabetes. The magnitude of effect from peer support, is not well understood in relation to pre-pregnancy counselling attendance, and could benefit from further work in understanding how peer support programmes might best fit with traditional health services.

As well as offering important support to women with type 1 diabetes, there might be benefits to peer-training for moderation of forums and social media groups, which could have cost-savings over the longer term. Certainly, peer support is widely accepted as an important part of health care in diabetes. A study (Aziz et al., 2018) evaluating the implementation of a cluster randomised controlled trial of a group-based, peer support programme to improve diabetes self-management in people with Type 2 Diabetes in Victoria, found that the trial reached a high proportion (79%) of its target population

through mailed invitations. Out of a total of 441 eligible people, 273 (61.9%) were willing to participate. The intervention fidelity was high (92.7%). The proportion of successful participants who had a reduction in 5 years cardiovascular disease risk score was 65.1 and 44.8% in the intervention and control arm respectively. Ninety-four percent (94%) of the intervention participants stated that the programme helped them manage their diabetes on a day to day basis. Overall, attending monthly group meetings provided 'a lot of support' to 57% and 'moderate' support to 34% of the participants.

Some studies comparing the effects of volunteer-led peer support with that of support and education led by health professionals have reported the same or better outcomes for the peer-support interventions - on both clinical and psychosocial outcomes (Gilbert, Dodson, Gill, & McKenzie, 2012). However, peer support has mostly been studied and defined as being complementary, rather than an alternative to, interventions led by health professionals. Support programmes that include both online and peer-led aspects are a growing phenomenon, due to the rapid changes in access to technology and social media (Gilbert et al., 2012), yet, research and evaluation of peer-support programmes which include volunteer-led or online programmes, are both extremely rare.

An Australian study (Gilbert et al., 2012) aimed to identify which key stakeholder groups (health professionals, people with diabetes, and both users of the programme and observers) most valued about the Reality Check online community. A secondary aim was to contribute the experiences from this internet-based forum, to the growing field of peer-support research. The study involved conducting online focus groups with both users and observers of the online community of people with type 1 diabetes and conducting an online survey of health professionals. Key results were that people with type 1 diabetes said the online community provided them with a wide range of supports, which were distinct to those they received via care provided by health professionals, and that it offered them a

complementary component to their lives that they valued highly as contributing to their ability to manage their diabetes (Gilbert et al., 2012). Health care professionals reported similar benefits as being valuable for their patients, but they did not highlight as many emotional and social supports, as people with type 1 diabetes had valued receiving from the programme. Although health care professionals and people with type 1 diabetes both identified "empathetic listening," "coping with social or emotional barriers," "feeling supported," and "connection and interaction with peers," people with diabetes also valued some additional types of support, including "encouragement," "staying motivated to reach their goals," "self-reflection," "a sense of community," and "assisting others" (Gilbert et al., 2012). This research is important to consider in light of the findings of this thesis and it is recommended that research is conducted which incorporates cost analysis for both users and providers, in relation to Internet-based programmes and services for women with type 1 diabetes and pregnancy, across a diverse range of women.

KEY POINTS AND FINAL WORD

As discussed, this thesis contributes important and novel insights to the currently small body of literature relating to pregnancy for women with type 1 diabetes. It has revealed that, not surprisingly, the pregnancy journey for some women with type 1 diabetes appears to have unique aspects, including more intense medicalisation and a need for early pregnancy planning. This has the potential to provide reassurance, but also might increase women's experiences of anxiety and distress. There are already potentially increased rates of anxiety and depression for women with type 1 diabetes and mental health is a critical issue to address from the outset. There is very little existing research considering diversity in relation to pregnancy and type 1 diabetes. Work is therefore required in relation to women from different cultural backgrounds, Aboriginal women, non-English speaking women, those with disabilities, single mothers, same-sex couples, across socio-economic

groups, across women with different levels of literacy, and those living in regional and rural locations.

It is clear from this work that pregnancy planning and pre-pregnancy counselling are very important in reducing the adverse outcomes of pregnancy for women with type 1 diabetes, yet women may not be aware that such services exist, may not be offered such services, or may lack access to them. Pre-Pregnancy counselling and pregnancy services should ideally be tailored to the changing needs and situation of each woman, and each pregnancy, with the provision of information via multiple sources, at regular intervals across the child bearing years - not just during pregnancy planning. Contemplation appears to be an important place to signpost to women that pre-pregnancy counselling exists, what it entails, and how it may benefit them and their unborn child. More knowledge about these issues is needed by both women with type 1 diabetes and health care professionals. Resources and policies need to support health care professionals to establish how pre-pregnancy counselling can best fit within their services and how to reach vulnerable groups.

The nature of communication about pregnancy between health care professionals and women with type 1 diabetes, has been presented as vitally important. More access to training in relation to person-centred communication about pregnancy for health care professionals supporting women with type 1 diabetes, might be beneficial. Women with type 1 diabetes may be less likely to attend pre-pregnancy counselling if they have been given only negative information, discouraged from pregnancy in the past, or judged for their choices. A trusting, non-judgemental relationship with at least one health care professional who is knowledgeable about pregnancy and type 1 diabetes, appears to be very important. Social supports are critical to a positive pregnancy experience for women with type 1 diabetes. This includes connection to other women with type 1 diabetes, contributing to and supporting each other's pregnancy journeys. Family and partner support, where

appropriate, also contributes to a more positive experience. Easy access to a variety of balanced pregnancy information, including internet-based programmes and resources, may be very helpful to some women, and ultimately result in significantly better outcomes for both mother and child.

In relation to next steps for this work, as the sample sizes for psychometric assessment of the Questionnaire developed in chapter 4 were small, it would be important, in particular, to collect data from a larger group of women, to test for reliability and other forms of validity. This would enable proper assessment of the internal consistency of the items in the Questionnaire, measuring the extent to which all items contribute equally to understanding the construct of preparedness for pregnancy. This would aim to fully assess the measurement properties of the Questionnaire, including assessment of validity (content validity, face validity, construct validity and criterion validity), reliability (repeatability and internal consistency) and responsiveness. This psychometric validation step is very important for such a tool to be accepted and widely used in the field (Anthoine, Moret, Regnault, Sébille, & Hardouin, 2014).

I recommend, therefore, that a number of potential studies could be carried out as described below. Whilst I could make suggestions on sample sizes, based on the number of births in Australia and percentage of women with type 1 diabetes, these would have to be calculated as pertains to the specific goals of any such work, to ensure they fit with the aims of those studies. The goal of sample size planning is to estimate an appropriate number of subjects for a given study design (Rao, 2012). Typically, at least 200 participants would allow for large-sample methods like factor analysis, and the more items or subscales that are included, then the larger the sample size should be. If there was to be an exploration of subgroups individually (e.g. type 1 and type 2), then the same number would be required within each of the subgroups. However, as previously stated, with such a small target

group, this can be problematic, and it is recommended that to overcome this issue, you start with a number of centres involved (Berg et al., 2018). Additionally, in order to achieve larger numbers of participants, it would be likely that women recruited would be at various time-phases of the pregnancy journey and, therefore, only small numbers could be followed from Pre-pregnancy (or Contemplation) to Motherhood. However, it would be useful to follow women from any time-phase to Motherhood. Given the relatively small numbers of women with type 1 diabetes who might be considering or planning pregnancy at any one time, and the difficulties stated in the literature in regards to research with this population, sample sizes might be therefore be smaller than are usually expected.

I suggest the following potential studies could be beneficial:

1) A qualitative study with a more diverse group of women with type 1 and type 2 diabetes, to consider the model of the pregnancy journey developed in chapter 3, in particular the primary themes experienced in each time-phase. This could include interviewing recruited women about their experiences across the pregnancy journey, to ascertain whether these fit with the themes identified in study one. Health care professionals could also be interviewed, to garner their perspectives. This would not have to be a study following the same women across time, although this would be the most beneficial. However, interviewing women about current or past experiences of the pregnancy journey at one point in time, would still be valuable.

2) A re-run of the pilot I carried out for the Questionnaire in chapter 4, again in a more diverse group, with both type 1 and type 2 diabetes. It is suggested to carry this out in partnership with a selection of diabetes centres, pre-pregnancy clinics and GP practices, recruiting women over 12 months - with the same outcomes, to test reliability and validity of the Questionnaire. Cognitive Interviews could be carried out prior to the women completing the Questionnaire. This would enable further examination of reliability,

acceptability and usefulness. The Questionnaire could be examined as part of a study considering the model of the journey of pregnancy as above in point 1 - being administered to any participants who identify that they are in the Contemplation and/or Pre-pregnancy phases. These women could then be followed across time to determine any positive impact of the Questionnaire. However, this work could also be carried out in a separate study, as per the pilot phase of this thesis.

3) A combined study in partnership with diabetes and pregnancy clinics, diabetes centres and GP practices across at least a 2-year period, recruiting women from Contemplation of pregnancy onwards, and following them across time. It is suggested the Questionnaire could be administered every 4-6 months for those in Contemplation or Pre-pregnancy, interviewing them from the second time-point, to see if there was any impact from the Questionnaire in relation to progression to pre-pregnancy counselling and preparedness for pregnancy. It is suggested all other women in the study could be interviewed (those at any stage of the pregnancy journey) each 4-6 months, to explore the issues they are experiencing at that time-phase, to examine the model of the pregnancy journey. This would also include the Questionnaire being attached to a website for clinicians and women and addition of a Facebook group for peer support, so that the benefits of web-based resources could be explored. This could be a newly developed website or the existing NDSS pregnancy and diabetes website.

Ideally, a multi-centre, longitudinal study, across a time-phase of at least 2 years, recruiting women from a diverse range of cultures and backgrounds, examining the issues that arise at each time-phase of the pregnancy journey; the benefits of the Questionnaire in Contemplation and Pregnancy Planning; and the role of web-based peer support, would provide rich information from which to broaden the scope of this work and enable the

findings to be put into practice, to improve the experiences and outcomes of pregnancy for all women with type 1 diabetes and their babies.

APPENDICES

CONTEMPLATING PREGNANCY IN DIABETES SUPPORT TOOL – FINAL PILOT VERSION

Before you start, we would like to know a little bit about you. Please answer all of the questions with your first response. The idea is to help and support you in preparing for a pregnancy should you decide you want to do that at some point. Even if you are unsure about whether you will want a baby at some stage, this is a helpful tool to make sure you have all the information and support you may need right now, and in the future.

- ***Do you think it is possible that you might be interested in having a child in the next 1 – 5 years? (Yes, No, Unsure) <u>If NO you do not need to continue the questions. If unsure or yes, please continue the survey.</u>***
- ***Do you think pre-pregnancy planning and care is important for women with diabetes? (Yes, No, Unsure).***
- ***Have you ever been pregnant? If so, how many times? (options from 0, 1, 2, 3, 4, 5, more than 5)***
- ***Were any of your prior pregnancies planned? (Yes, No, Unsure, Not Applicable)***
- ***Have you ever had diabetes during any of your pregnancies? If so, how many times? (options from 0, 1, 2, 3, 4, 5, more than 5)***
- ***Do you have any biological children? If so, how many? (1, 2, 3, 4, 5, 6, more than 6)***
- ***What is your age? (select from age ranges)***
- ***Have you ever had diabetes during the time you were planning a pregnancy? (yes/no/not sure)***
- ***What type of diabetes do you have? (drop down box – type 1, type 2, other, unsure)***
- ***When were you diagnosed with diabetes? (under 12 months ago, 1 year – 5 years ago, 6 – 10 years ago, 11 – 15 years ago, 16 – 20 years ago, over 20 years ago, unsure)***

- ***Do you know your most recent HbA1c? If so, please select from the following (HbA1c % selections)***
- ***Do you experience hypoglycaemia (low blood glucose)? (Yes, No, Unsure)***
- ***Do you monitor your blood glucose? If so, how are you monitoring it (e.g. finger pricks or continuous glucose monitoring)***
- ***How often do you monitor your blood glucose each day? (I am on a CGM; 0, 1, 2, 3, 4, more than 4)***
- ***Do you know if you have any of the following diabetes related complications? Please select all that apply (options with tick box)***
- ***Are you having regular checks for the following diabetes complications? Please select all that apply (options with tick box)***
- ***How are you currently managing your diabetes? Please select all that apply. (tick boxes with options – tablets, insulin injections, insulin pump, blood glucose monitoring, continuous glucose monitoring, other)***
- ***What is the make-up of your household? (Live at home with parents, live alone, live with friends, live with partner, other - please write in)***
- ***Do you live in a rural or regional area? (Yes, No)***
- ***Have you ever visited with a diabetes and pregnancy clinic or specialist? (Yes, No, Unsure)***

We would like to understand what you know about the recommended steps in planning and managing pregnancy when you have diabetes, and how important these things are to you. If you were to get pregnant in the next 1-5 years, how important would the following actions be to you? Please indicate your response to the following as - Very Important, Important, Neither Important or Unimportant, Unimportant, Very Unimportant.

If and when I decide I want to have a baby, I will take the following actions before starting to plan my pregnancy:

1. ***Talk with my diabetes care team about what steps to take in preparing for pregnancy***
2. ***Use contraception until I talk with my diabetes team about planning for pregnancy***
3. ***Talk with my health care team about the target for my HbA1c before I start planning for pregnancy***
4. ***Take high dose (5mg) folic acid prior to and during my early pregnancy [from and up to the time advised]***
5. ***Stop or change any potentially harmful medications I may be taking before pregnancy, as recommended by my doctor***
6. ***Manage my diabetes with the latest technology available such as insulin pumps and continuous glucose monitors***
7. ***Have routine checks for diabetes complications such as retinopathy and kidney health***
8. ***Have a fitness assessment at my local gym or health centre***
9. ***Even if I have already had a baby, see my diabetes team for pre-pregnancy care***
10. ***Reduce my alcohol consumption to the recommended safe drinking levels for women when planning a pregnancy, and to zero once pregnant***
11. ***Work with my health care team to achieve healthy blood pressure levels***
12. ***See my doctor for a review of all medications I am taking, including complementary medicines and supplements***
13. ***Discuss a healthy exercise and eating plan with my diabetes team***
14. ***Speak with my health care team about how I am feeling about my diabetes, and any concerns I have about how it may affect pregnancy***

Planning a pregnancy with diabetes requires a range of personal and social supports and resources. We would like to understand for you, what things might get in the way, and

what things might make it possible, for you to have a healthy pregnancy and baby. Rate how often the following statements apply to you (all of the time, some of the time, unsure, a little of the time, none of the time).

If and when I decide I would like to have a baby, I think that:

15. ***Looking after my emotional wellbeing and mental health would be just as important as caring for my physical health***
16. ***I would worry about changes to my diabetes management during pregnancy***
17. ***I would worry about the impact the effort of managing diabetes during pregnancy would have on my loved ones***
18. ***I would worry about the impact of my diabetes on my baby***
19. ***It would be too demanding to achieve blood glucose levels within the target range before conceiving***
20. ***It would be too demanding to maintain target diabetes management throughout pregnancy***
21. ***I might not be able to continue my daily work or other activities when managing diabetes and pregnancy***
22. ***I would be overwhelmed by all the things I need to do to plan and prepare for pregnancy***
23. ***Being connected to other people with diabetes via social media and other websites would be helpful for my wellbeing***
24. ***I would feel confident about managing diabetes during pregnancy***
25. ***In general, I could be open with my health care team about any struggles I have with diabetes and not feel judged***
26. ***The focus on my diabetes would make it hard to have a positive pregnancy experience***
27. ***My family would be supportive of my desire to have a baby***
28. ***My family may want to be too involved in my diabetes management during pregnancy***

29. ***I already have a team of health care professionals who understand diabetes and pregnancy to support me when ready***
30. ***I might feel isolated from people who understand what is needed in managing diabetes and planning a pregnancy***
31. ***I would use diabetes related websites and social media groups for information and support about pregnancy and diabetes***
32. ***I would use general pregnancy websites and resources for information and support***
33. ***Being connected to other women with diabetes who have been through pregnancy would be important to me***

PARTICIPANT INFORMATION AND RECRUITMENT DOCUMENTS

Social Media posts and flier

Are you a woman with type 1 or type 2 diabetes who may one day consider having a baby? Maybe you are really not sure, but have thought about it? If you are considering a pregnancy in the next 1-5 years, are aged 18 – 40 years and speak English, we would like your help in our research project! We are developing a survey tool for women with type 1 and type 2 diabetes to use with their health care team in considering pregnancy. Pre-pregnancy counselling can help women with diabetes in planning their pregnancy. The survey tool aims to help understand more about your current knowledge about diabetes and pregnancy; your current diabetes management and general health; your current mental health and wellbeing; and level of support from partner, family, other women with diabetes and health care professionals. The aim is to encourage discussion about how the health care team can best support you to take steps towards planning a pregnancy at some stage in the future. Even if you are unsure if you want to have a baby one day, it is a useful exercise to find out more about what may be important. All you will need to do is to complete the survey for us, so we can see if it will be helpful. A small number of women will be asked to participate in an interview as well. The project has ethics approval from Adelaide University

and all information will be provided to women who get involved. Please get in touch with me via helen.edwards@adelaide.edu.au or send me a direct message here if you would like more information.

Are you a woman with type 1 or type 2 diabetes who may one day consider having a baby? Maybe you are really not sure, but have thought about it? If you are considering a pregnancy in the next 1-5 years, are aged 18 – 40 years and speak English, we would like your help in our research project! We are developing a survey tool for women with type 1 and type 2 diabetes to use with their health care team in considering pregnancy. Pre-pregnancy counselling can help women with diabetes in planning their pregnancy. The survey tool aims to help understand more about your current knowledge about diabetes and pregnancy; your current diabetes management and general health; your current mental health and wellbeing; and level of support from partner, family, other women with diabetes and health care professionals. The aim is to encourage discussion about how the health care team can best support you to take steps towards planning a pregnancy at some stage in the future. Even if you are unsure if you want to have a baby one day, it is a useful exercise to

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If you have diabetes and would love to help develop a new survey tool for women with type 1 and type 2 diabetes to better prepare for pregnancy, we would love to hear from you! As part of my PhD work, I am developing a survey tool that diabetes health care professionals can use with women, well before they start planning a pregnancy. All you will need to do is to complete the survey for us, so we can see if it makes sense and will be helpful. A small number of women will be asked to participate in an interview as well. Please get in touch with me at helen.edwards@adelaide.edu.au for more information or send me a direct message. The project has ethics approval from the Adelaide University.

PARTICIPANT INFORMATION SHEET – WOMEN WITH DIABETES

PROJECT TITLE:

Development of a Contemplating Pregnancy in Diabetes Support Tool

HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER: H-2017-***

PRINCIPAL INVESTIGATOR: Professor Deborah Turnbull

STUDENT RESEARCHER: Helen Edwards

STUDENT'S DEGREE: PhD Psychology/Health and Medical Sciences

Dear Participant,

You are invited to participate in the research project described below.

What is the project about?

We are developing a Contemplating Pregnancy in Diabetes Support Tool to determine preparedness for pregnancy. The aim is for the tool to be used by diabetes health care providers with women with type 1 and type 2 diabetes, when contemplating pregnancy within the next 1 – 5 years. Pre-pregnancy counselling can help women in planning their pregnancy. However, lots of women do not attend pre-pregnancy counselling for different reasons. This can include not knowing the importance and usefulness of pre-pregnancy counselling, not having access to this, thinking they already know all they need, or having past negative experiences around pregnancy information. The survey tool aims to help with increasing awareness about the importance of pre-pregnancy counselling and encourage women to attend this when ready to plan a pregnancy.

The survey results would be used to have a discussion about how the health care team can best support the woman to take steps towards planning a pregnancy at some stage in the future. Even if she is unsure if she wants to have a baby one day, it is a useful exercise to find out more about what may be important. The tool would be used in a cycle of care, such as every 6 – 12 months when visiting her doctor or diabetes educator.

Who is undertaking the project?

This project is being conducted by Helen Edwards as part of her PhD research and her supervisors Professor Deborah Turnbull, Professor Michael Horowitz and Dr William Polonsky. This research will form the basis for the degree of PhD at the University of Adelaide.

Why am I being invited to participate?

We have invited you to participate because you are a woman with either type 1 or type 2 diabetes between 18 and 40 years of age, live in Australia and speak English.

What will I be asked to do?

If you agree to participate in the research, we will ask you to do the following:

- Complete the survey tool online – this will consist of about 40 questions with options for you to respond. It will be around your thoughts and feelings around pregnancy and your diabetes
- A small number of women will then be invited to participate in a video interview via skype with Helen Edwards. We will randomly select these women, and invite them to join. If agreed, the questions for the interview will be provided to you prior to the interview, and Helen will then set up a time that suits you to carry out the interview.

How much time will the project take?

We expect the survey to take you no more than 30 - 45 minutes to complete. There are no further requirements unless you are one of a small number of women who are invited for an interview. If so, an interview will take about 2 hours and will be conducted online.

Are there any risks associated with participating in this project?

There are no foreseeable risks of being involved in this project. However, it is possible you may feel a range of emotions around pregnancy, and your diabetes. If you do experience any distress from completing the survey and/or interview, we can refer you to someone for some counselling.

What are the benefits of the research project?

This research may result in the development of a tool that will make a difference to the experience and journey of pregnancy for women with diabetes. It may assist in increasing uptake of pre-pregnancy counselling services when women are ready to plan a pregnancy.

Can I withdraw from the project?

Participation in this project is completely voluntary. If you agree to participate, you can withdraw from the study at any time, however you can only withdraw your data from the survey up until thesis submission.

What will happen to my information?

Any information provided and all project records will be confidentially stored on an Adelaide University secure database. The research team will be the only ones with access to this information and it will be kept for a minimum of 5 years. Data will also be securely stored at Helen Edwards home office in locked storage. Information and results will be

reported and publicised via journal articles, Helen Edwards PhD thesis, and presentations at workshops and conferences. It will also be shared via social media and blogs. Participants will not be identified in any way in any publications, and general results will be shared only. All participants will be provided with links to any publication of results.

Who do I contact if I have questions about the project?

If you have any questions at any time you can contact Helen Edwards on 0410 301267 or helen.edwards@adelaide.edu.au

What if I have a complaint or any concerns?

The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2017-xxx). If you have questions or problems associated with the practical aspects of your participation in the project, or wish to raise a concern or complaint about the project, then you should consult the Principal Investigator. If you wish to speak with an independent person regarding a concern or complaint, the University's policy on research involving human participants, or your rights as a participant, please contact the Human Research Ethics Committee's Secretariat on:

Phone:

Email:

Post: Level 4, Rundle Mall Plaza, 50 Rundle Mall, ADELAIDE SA 5000

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

If I want to participate, what do I do?

If you want to join our study you will need to complete the consent forms and then you will be sent links and information about completing the survey tool online. If you are selected for an interview, we will get in touch to arrange this. You are under no requirement to agree to an interview should you be invited.

Yours sincerely,

Helen Edwards PhD Candidate

Professor Deborah Turnbull

Professor Michael Horowitz

Dr William Polonsky

Adelaide University

PARTICIPANT INFORMATION SHEET – EXPERT PANEL FOR CONTENT REVIEW

PROJECT TITLE:

Development of a Contemplating Pregnancy in Diabetes Support Tool

HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER: H-2017-***

PRINCIPAL INVESTIGATOR: Professor Deborah Turnbull

STUDENT RESEARCHER: Helen Edwards

STUDENT'S DEGREE: PhD Psychology/Health and Medical Sciences

Dear Participant,

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What is the project about?

We are developing a Contemplating Pregnancy in Diabetes Support Tool to determine preparedness for pregnancy. The aim is for the tool to be used by diabetes health care providers with women with type 1 and type 2 diabetes, when contemplating pregnancy within the next 1 – 5 years. Pre-pregnancy counselling can help women in planning their pregnancy. However, lots of women do not attend pre-pregnancy counselling for different reasons. This can include not knowing the importance and usefulness of pre-pregnancy counselling, not having access to this, thinking they already know all they need, or having past negative experiences around pregnancy information. The survey tool aims to help with increasing awareness about the importance of pre-pregnancy counselling and encourage women to attend this when ready to plan a pregnancy.

The survey results would be used to have a discussion about how the health care team can best support the woman to take steps towards planning a pregnancy at some stage in the future. Even if she is unsure if she wants to have a baby one day, it is a useful exercise to find out more about what may be important. The tool would be used in a cycle of care, such as every 6 – 12 months when visiting her doctor or diabetes educator.

The tool will assess at any gaps in knowledge and understanding about:

- how diabetes and pregnancy impact on each other
- the risks involved in pregnancy for women with diabetes
- how to prevent negative outcomes
- specific steps needed in planning a healthy pregnancy.

The tool will help to understand:

- the value placed by the woman on various health behaviours needed to plan and have a healthy pregnancy and baby with diabetes
- her current diabetes management and health
- her preparedness to take the steps needed
- her awareness and willingness to attend pre-pregnancy counselling
- her current access to technology and tools to manage diabetes

The tool will consider:

- her current mental health
- her level worry about pregnancy and diabetes
- her beliefs and thoughts about pregnancy and becoming a mother
- any current distress that may need addressing
- her level of self-efficacy, confidence and optimism in relation to diabetes and pregnancy.

Finally, the tool will consider:

- social support and connection to other women with diabetes around pregnancy
- assessment of current support from partner
- assessment of current support from family
- assessment of current support from health care team
- any gaps in support and any need to access increased or different support
- if any support may have any negative impacts and how to address this

The survey results would then be used to have a discussion about how the health care team can best support the woman to take steps towards planning a pregnancy at some stage in the future. Even if she is unsure if she wants to have a baby one day, it is a useful exercise to find out more about what may be important. The tool would be used in a cycle of care, such as every 6 – 12 months when visiting her doctor or diabetes educator.

Who is undertaking the project?

This project is being conducted by Helen Edwards as part of her PhD research and her supervisors Professor Deborah Turnbull, Professor Michael Horowitz and Dr William Polonsky. This research will form the basis for the degree of PhD at the University of Adelaide.

Why am I being invited to participate (expert panel)?

We have invited you to participate as part of our expert review and evaluation of content validity, because you are a consumer rep, health care professional or other expert in diabetes

and/or diabetes and pregnancy, who can help us to determine if our survey tool makes sense, is useful and includes relevant items.

What will I be asked to do?

If you agree to participate, we will ask you to do the following:

- we will send you a copy of the survey questions via email
- we will ask you to read and evaluate the question/survey tool via email
- We will ask you to provide written feedback to Helen Edwards about the survey tool around content validity
- This will be prompted through a series of questions to enable you to provide us with this feedback

How much time will the project take?

We expect the task to take you no more than 1- 2 hours to complete. There are no further requirements.

Are there any risks associated with participating in this project?

There are no foreseeable risks of being involved in this project. Should you suffer any adverse events, such as feeling distressed after considering any feelings about pregnancy and/or diabetes, we can refer you to someone for some counselling.

What are the benefits of the research project?

This research may result in the development of a tool that will make a difference to the experience and journey of pregnancy for women with diabetes. It may assist in increasing uptake of pre-pregnancy counselling services when women are ready to plan a pregnancy.

Can I withdraw from the project?

Participation in this project is completely voluntary. If you agree to participate, you can withdraw from the study at any time, however you can only withdraw your comments about the survey up until thesis submission.

What will happen to my information?

Any information provided and all project records will be confidentially stored on an Adelaide University secure database. The research team will be the only ones with access to this information and it will be kept for a minimum of 5 years. Data will also be securely stored at Helen Edwards home office in locked storage. Information and results will be reported and publicised via journal articles, Helen Edwards PhD thesis, and presentations at workshops and conferences. It will also be shared via social media and blogs. Participants

will not be identified in any way in any publications, and general results will be shared only. All participants will be provided with links to any publication of results.

Who do I contact if I have questions about the project?

If you have any questions at any time you can contact Helen Edwards on 0410 301267 or helen.edwards@adelaide.edu.au

What if I have a complaint or any concerns?

The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2017-xxx). If you have questions or problems associated with the practical aspects of your participation in the project, or wish to raise a concern or complaint about the project, then you should consult the Principal Investigator. If you wish to speak with an independent person regarding a concern or complaint, the University's policy on research involving human participants, or your rights as a participant, please contact the Human Research Ethics Committee's Secretariat on:

Phone:

Email:

Post: Level 4, Rundle Mall Plaza, 50 Rundle Mall, ADELAIDE SA 5000

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

If I want to participate, what do I do?

If you want to join us to help in our study you will need to complete the consent forms and then you will be sent the survey questions and the things, we would like you to assess.

Yours sincerely,

Helen Edwards PhD Candidate

Professor Deborah Turnbull

Professor Michael Horowitz

Dr William Polonsky

Adelaide University

LETTER FOR CLINICS, HEALTH CARE PROFESSIONALS AND PROFESSIONAL BODIES

Dear

I am writing to you with some information about a research study I am undertaking as part of my PhD – Developing a Contemplating Pregnancy in Diabetes Support Tool. We are developing a Survey Tool to determine preparedness for pregnancy, that can be used by diabetes health care providers with women with type 1 and type 2 diabetes, when contemplating pregnancy within the next 1 – 5 years. We know women with diabetes who attend pre-pregnancy counselling to plan their pregnancy have much better outcomes for themselves and their babies. However, lots of women do not attend pre-pregnancy counselling. This is for lots of different reasons, but they include not knowing the importance and usefulness of pre-pregnancy counselling, not having access to this, thinking they already know all they need, or having past negative experiences around pregnancy information. The survey tool aims to help with increasing awareness about the importance of pre-pregnancy counselling and encourage women to attend this when ready to plan a pregnancy. The tool aims to understand more about a woman's current knowledge about diabetes and pregnancy; the impact of her current diabetes management and general health; her current mental health and wellbeing; and level of support from partner, family, other women with diabetes and health care professionals.

The tool will assess at any gaps in knowledge and understanding about:

- how diabetes and pregnancy impact on each other
- the risks involved in pregnancy for women with diabetes
- how to prevent negative outcomes
- specific steps needed in planning a healthy pregnancy.

The tool will help to understand:

- the value placed by the woman on various health behaviours needed to plan and have a healthy pregnancy and baby with diabetes
- her current diabetes management and health
- her preparedness to take the steps needed
- her awareness and willingness to attend pre-pregnancy counselling
- her current access to technology and tools to manage diabetes

The tool will consider:

- her current mental health
- her level worry about pregnancy and diabetes
- her beliefs and thoughts about pregnancy and becoming a mother
- any current distress that may need addressing
- her level of self-efficacy, confidence and optimism in relation to diabetes and pregnancy.

Finally, the tool will consider:

- social support and connection to other women with diabetes around pregnancy
- assessment of current support from partner
- assessment of current support from family
- assessment of current support from health care team
- any gaps in support and any need to access increased or different support
- if any support may have any negative impacts and how to address this

The survey results would then be used to have a discussion about how the health care team can best support the woman to take steps towards planning a pregnancy at some stage in the future. Even if she is unsure if she wants to have a baby one day, it is a useful exercise to find out more about what may be important. The tool would be used in a cycle of care, such as every 6 – 12 months when visiting her doctor or diabetes educator. This project is being conducted by me as part of my PhD research and my supervisors Professor Deborah Turnbull, Professor Michael Horowitz and Dr William Polonsky. This research will form the basis for the degree of PhD at the University of Adelaide. The research has been approved by ethics. I would love it if you could share with your colleagues via social and professional networks, and women with diabetes who are in your practice, to assist us in recruitment to the study. Please advise any potential participants that no personal information will be passed on to the researchers by yourself, and they should get in contact with me to obtain further information.

Please feel free to forward this email to colleagues. I am happy to speak further with you so please get in contact for a chat about the study. I have attached the participant information sheet so you can see more about what is expected for participants; a flyer you can print to pin up in your practice rooms or waiting areas, as well as images you can use in any email mail outs to colleagues, clients, and use on social media. Please let me know if you need any further information or have any questions

Thanks for your time

Warm regards

Helen Edwards

PhD Candidate

BASW(Hons); Diabetes Ed (Grad Cert)

HUMAN RESEARCH ETHICS COMMITTEE (HREC)

CONSENT FORM

Title:	**Development of a Contemplating Pregnancy in Diabetes Support Tool**
Ethics Approval Number:	

1. I have read the attached Information Sheet and agree to take part in the following research project:
2. I have had the project, so far as it affects me, fully explained to my satisfaction by the research worker. My consent is given freely.
3. I have been given the opportunity to have a member of my family or a friend present while the project was explained to me.
4. Although I understand that the purpose of this research project is to improve the quality of medical care, it has also been explained that my involvement may not be of any benefit to me.
5. I have been informed that, while information gained during the study may be published, I will not be identified and my personal results will not be divulged.
6. I understand that I am free to withdraw from the project at any time and that this will not affect medical advice in the management of my health, now or in the future.
7. I agree to the interview being audio/video recorded. Yes ☐ No ☐
8. I am aware that I should keep a copy of this Consent Form, when completed, and the attached Information Sheet.

Participant to complete:

Name: Signature: Date:

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